

Introduction

Cancer is a serious health challenge in Finland. Today every fourth person is expected to fall ill with cancer at some stage of his or her life. Although cancer is not a new illness in humanity's history, during the past decades the number of cancer patients has grown radically, partly because of changing lifestyles but also because of environmental problems and work conditions. The rise in the rates of cancer diagnosis is also explainable because diagnosis techniques have become more advanced and the state has begun to support regular check-ups and follow-ups for certain risk groups. Nevertheless, what exactly the reasons are for contracting cancer is still unclear. This lack of clarity regarding cancer's origin certainly affects the popular understanding of the disease. Accordingly, cancer narratives present a fascinating mixture of ideas deriving from scientific discoveries, popular knowledge and personal experience.

Above all, cancer narratives demonstrate that having cancer in many ways changes an individual's life. The culturally determined transformation from an ordinary, or normal, person into a cancer patient, forces people to re-negotiate their self image, their understanding of life and their place in the everyday milieu. Cancer narratives show that the word cancer causes fear and confusion, and evokes an image of painful and inescapable death. The various social misjudgements are one of the greatest challenges to all cancer patients. Therefore, people must carefully choose how, when and with whom they share their cancer experience. Considering this situation, written cancer narratives function as mediators of individual thought, experience and emotions relating to cancer. In addition, these texts form a good source from which to study the representations of culture-bound ideas regarding cancer in various contexts. Accordingly, cancer narratives form an excellent source for the examination of the individual and cultural

aspects of this particular illness, whereas for cancer patients, composing a cancer narrative may become a path by which to regain the *self*.

The ideas for studies often emerge from interaction between a researcher's substantive interests, intimate knowledge, and the information contained in the research materials. Above all, the general selection of research topic for this thesis is based on my personal interest in narration and narrating where it concerns illness experience. Naturally, this particular interest has its history. When I turned twenty my mother was diagnosed with cancer. From this dreadful time I recall only one overwhelming thought – my mother is going to die. The image of death was inseparably connected to the word 'cancer' in my mind. Because of this image I could not believe that my mother would be well again. As a matter of fact, the only thing I knew about cancer was that everyone having it was going to die soon. My fear was so great that I never discussed it with my mother or anyone else in my family. I was able to share this thought only with my best friend, who had already lost her mother to cancer at the age of six.

The years passed and my mother was still with us. However, her depression and fear of a reoccurrence of her cancer raised multiple questions in me. I could not understand why it was so difficult to accept being healthy again when the cancer had officially been cured. I could not understand why my mother continued to be depressed, worried and suspicious about any minor bodily concern. I could not understand why she did not let go and continue living as she had done before her illness. I could not understand what had changed in her life and how, and was it all because of cancer?

As a folklore student at the University of Tartu, Estonia, I became interested in folk belief, narration and folk medicine. I worked with folk images of ague (malaria), at first in Estonia, and also since 1999, in Finland (Paal 2004). The materials on ague, preserved in the archives, were interesting and appealing, however, various questions came to trouble me during my research. I was not sure how well I could interpret ague-related texts, or whether an interpretation was possible at all without having access to the thoughts and feelings of the people who composed these stories. I was not sure what the meaning of ague was in rural society or what the true aim of the belief legends that talked about this folk illness was. All I understood was that finding answers to these questions was complicated, since the tradition has

gone together with its carriers and there was no context that could extend my awareness. I realised that no medical history book can tell me about the inner thoughts and feelings of people who suffered from the ague at the beginning of the 19th century, and thus, no archive text could help me understand individual considerations relating to the illness experience.

In spring 2003 I found a text in the Finnish Folklore Archive about healing the ague. The text talked about a woman who, during the healing process, was pulled through a coffin in a graveyard. Although she got rid of the ague, a nail inside the coffin scratched her and caused a new illness, which was called '*ruumiin koi*' (body moth). I grasped for an ethnographical dictionary, which revealed that the 'body moth' was a name for cancer in Finnish folk medicine. From that moment on, I knew what my next research topic was going to be. It was going to be cancer and its representations in folk narratives.

I was pleasantly surprised when I discovered that in 1994 the Finnish Folklore Archive and cancer patients' support establishments had arranged a writing competition entitled *Kun sairastuin syöpään* (when I fell ill with cancer). In the context of the writing competition the respondents were encouraged to share their emotions, feelings, and thoughts concerning their cancer experiences. For me, discovering this material, containing 6000 pages of written cancer narratives from 672 respondents, meant that I was given an opportunity to examine, and hopefully also understand, what was going on when a person becomes ill with cancer.

Over the past years I have read numerous studies dealing with illnesses and their representations in narrative. Perhaps the most inspiring book for me was *Once Upon a Virus* (2004) by Diane E. Goldstein. Goldstein's study deals with AIDS legends, analysing the meaning and the position of narratives in the everyday context. She has proposed that texts communicating vernacular health issues "are not just entertaining tidbits of dinner conversation but rather the incredibly powerful core of personal and collective action" (Goldstein 2004, 157). Goldstein argues that people are not slaves to the stories they hear, meaning that we do not think that told narratives are the supreme truth. However, the narratives about illnesses unite culture and understanding and contain the representations of health truths that influence people's health choices and arguments in everyday life. The truths and views that become represented as individual interpreta-

tions in such narratives represent the particular discourse influenced by language (ideologies) and culture framed by the institutional arrangement of a particular society.

The narrative approach in this thesis is based on the idea that narrating and narratives act as a 'root metaphor' for many different aspects of human life (Mattingly 1998, 86). In case of illness the narrative concentrates on the illness process, particularly on the moment of diagnosis, pathological drama, and the final outcome – recovery or death (Sacks 2007, ix–x). The moment of diagnosis causes a transformation that marks a turn in an individual life. The pathological drama represents the healing ritual (treatments) that is applied to cure the illness and return to normal life. Despite all human efforts the final outcome is uncertain in cases of cancer. More importantly, the individual experience is also in many ways different from the culture-bound expectations people have as they receive their cancer diagnosis. The narrative approach makes it possible to study human reasoning, emotions and experience in an everyday context as well as considering significant events in a particular culturally defined context.

The thesis is organised as a series of analyses dealing with representations of the cancer experience and their significance in the particular context. The thesis follows the general course of illness from the moment of diagnosis until the final solution to the individual cancer experience. In this work I analyse various extended secondary and primary narratives as segments of self-expression to present the respondents' thoughts, feeling and experiences relating to their illness experience. By doing so I shall point out the particular tendencies characteristic to cancer narratives. Because of the uniqueness of every cancer experience the cancer narratives are also unique in many ways, although they all follow the course of the illness. This also 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 that make the narrative comprehensible and meaningful.

In the first chapter I introduce the research aims and materials. For those interested in cancer experience representations, I suggest that they continue reading from chapter three as the most significant methodological issues are repeated at the beginning of each chapter. However, the detailed overview of the research material is significant to understanding the values of the analysed source material. By rais-

ing methodological issues in the first chapter I aim to highlight the possibilities present when analysing thematic narratives within the folklore paradigm.

Chapter 2 examines the written cancer narratives, pointing out the significance of writing down the illness experience as a method for coping with, and analysing, one's illness process. Above all it is the need to discuss one's illness that makes people compose illness narratives. Although the motivations and styles are different, in their writing people express many important individual and culture-bound factors dealing with the period of their cancer. Although general expectations towards written narratives proceed from the image of narrative as a meaningful, coherent and finalised method of self-expression, the cancer narratives collected via the writing competition prove to be different in many ways.

Chapter 3 analyses folk medical records originating from the Finnish Folklore Archive. This part of the thesis introduces the significance of cancer in Finnish folk medicine. It describes folk medical images of cancer's origin as well as its cures and treatments. The aim of this diachronic insight is to point out the development of cancer's significance – alongside discoveries in modern medicine – into a serious health problem.

Chapter 4 analyses three cancer narratives as thematic wholes. The central goal of this chapter is to compare three narratives in order to draw out the important similarities and differences between these representations of the illness experience. It analyses the structure of the cancer narratives and the characteristic spatio-temporal 'knots' that are used to mediate the meaning. It also concentrates on the authorial 'voicing' used to express individual, culture-bound and societal aspects of the cancer experience in different milieux. In this chapter, cancer patients' narratives are approached as 'wholes' built on 'dialogic imagination'.

Chapter 5 introduces the cultural stigma surrounding cancer as an illness and as an experience. Discussion in this chapter of culture-bound attitudes towards the illness from an ethnomedical point of view aims to highlight the particular nature of cancer as a modern mythological illness, which in many ways stigmatises the illness carrier.

Chapter 6 focuses on the moment of diagnosis. This moment is represented in cancer narratives as emotionally the most difficult moment

during the illness process. In their writings, respondents use various metaphors to express their emotions at that particular time. These metaphors may be approached as miniature works that represent the transformation from an ordinary person into a – stigmatised – cancer patient. On the other hand, metaphors also work as ‘culturally bound keys’ to emotions and therefore should not be overlooked, even within these thematic narratives.

Chapter 7 discusses the situation of cancer patients as they encounter the ‘rites of passage’ that society offers them in order that they become well again. The time spent in hospital is described not only as a time of bodily alteration, but also as representing a period of time in which there is a ‘looseness’ of self. This feeling of looseness is a result of entering a new social setting, a temporary community of sufferers. Daily life in healthcare institutions follows its own rules and people governed by these rules feel themselves insignificant as individuals. This chapter emphasises the patient’s need for the human touch, which may be established through communication with other patients. In particular, narratives written during the healing process become significant and offer the opportunity of analysing and reinterpreting the situation as the years go by.

Chapter 8 continues to examine the methods of identity alteration used to find self-help strategies. This chapter studies the use of complementary and alternative self-help methods among Finnish cancer patients. The lack of patient-doctor communication prompts patients to search for alternative paths to recovery. Cancer patients claim that making such decisions creates even more stress and fear, as people are very loyal to the treatments offered by evidence-based medicine, and at the same time doctors refuse to discuss other opportunities. Thus, patients struggle to use complementary self-help methods in secret, which is an interesting ethnographic phenomenon, although in everyday life this struggle increases the amount of psychological and bodily suffering.

Chapter 9 demonstrates another opportunity to communicate emotionally complex issues and suppressed ideas concerning the individual illness experience. It seems natural that people discuss their dreams and dream-like feelings, even if they are connected to illnesses or even death. Dream events become interpreted in terms of waking experience and become in themselves significant narratives connected to the ill-

ness experience. Such meaningful narratives remain significant even years later and become good tools by which to mediate the fear and confusion that surround the illness process.

Above all, this work is about patients and their points of view. It concentrates on patients' 'voicings', which are important in order to make the cancer experience understandable and 'open' in the current cultural and societal setting. When following this thesis one should bear in mind that it is the work of a folklorist who is specialised in illness narratives and traditional traits occurring in narrative representations. 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.

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WRITTEN CANCER NARRATIVES

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