

10. The Study of Written Cancer Narratives: Comments and Conclusions

What happens when people are diagnosed with cancer? How do cancer patients cope with their illness and how do they manage their daily lives? To answer these and several other questions dealing with cancer I read and analysed 672 written narratives from the Finnish Folklore Archive, collected in 1994. Above all, the cancer narratives demonstrate that whatever the official medical explanation and treatment might be, patients come up with their own explanations and search for complementary methods of self-help to cope with their illness. In the patients' interpretations, the origins of cancer are connected to an individual's life path and lived experience. This is an important concept that should be noted, for example, in order to establish a functioning patient-doctor relationship and to lessen cancer patients' suffering.

The patients' points of view seems significant as the written cancer narratives – short pathographies – differ greatly from the pathologies provided by socially approved biomedicine. Because of my approach as a folklorist, I have studied cancer patients' thoughts, experiences and feelings from the cultural perspective. However, it is difficult to draw any conclusions without thinking of the dominant developments in the social, political, economic and medical worlds, which have a significant affect on patients' positions in society. I suggest that observing the important changes in society from different perspectives shows how every historical era has characteristic illnesses reflecting the societal and cultural setting of the time. Furthermore, cancer narratives shed

light on questions about the meaning of cancer at societal and institutional levels.

The cancer narratives studied in this thesis reveal patients' individual approaches to the challenge of having cancer, as well as various culture-bound beliefs, fears, myths and other significant ideological images about being ill. Thus, the writing sent to the folklore archive form a valuable ethnographic source with which to study cancer as an illness and its significance from the cultural perspective. For this reason, I use an ethnomedical approach in order to examine what kind of illness cancer is and how it has been perceived in Finnish culture over the past century. This includes study of the ethnomedical accounts of cancer from the second half of the 19th century, as well as current Internet discussions on the Forum for Finnish Cancer Patients. These sources form an extended context within which to observe the change in popular reasoning against the background of a rapidly changing sociocultural setting.

The understanding of particular cultural settings seems essential in order to analyse cancer narratives properly. This study, based on cancer narratives, demonstrates that individual experience differs in many ways from cultural expectation. Quite often writers even attempt to deny pre-set thoughts and ideas of this kind, based on their individual reasoning and life experience. Naturally, it is difficult to decide which authorial voicing belongs to the external, such as culture- and language-bound ideologies, and which to the internal or personal set of cancer-related ideas. Authorial speech in cancer narratives could be interpreted as a continuous negotiation or imaginary dialogue between the personal voice and culture-bound ideas that result in authorial evaluation of the situation. To analyse and exemplify such evaluations in written texts I ask how people express their thoughts, feelings and experiences regarding cancer, and why so? The analytical units discussed in this work derive from the large text corpus representing the themes and issues that are discussed repeatedly. Thus, I suggest these are issues that cancer patients are often confronted with in everyday life; whereas narrative representation offers an insight into the important issues in cancer patients' lives. Issues that are usually covered by significant silence and therefore not discussed.

The historical development of popular cancer discourse

Since the second half of the 20th century cancer has become a dominant disease in Western countries, endangering people regardless of age group, gender, race or social status. Every year almost eight million people die from cancer worldwide. Thus, a comparison with plague is not exaggerated, although, according to current medical knowledge cancer is not an endemic disease. This does not stop people from thinking cancer might be in some ways contagious. According to the evolutionary approach, there are several ecological aspects connected with the occurrences of cancer. Furthermore, new medications in use, such as antibiotics, have greatly affected human life expectancy, making cancers in old age more common than ever before. As pointed out in chapters five, *Popular Images of Cancer in Modern Discourse* and eight, *Methods of Coping and Alternative or Complementary Self-Help*, cancer rates are higher because of increased awareness. Interestingly enough the development of diagnostic techniques, which help the early detection of cancer, has also caused an increase in cancer rates.

Nevertheless, my study, based on ethnomedical records, points out that cancer has been a health problem for a long time. The previous lack of diagnostic tools meant that like doctors of the time, ordinary people also recognised cancer only when it was manually or visually detectable. As I have discussed in chapter four, *Cancer in Finnish Folk Medicine*, because of limited knowledge, people were unable to separate cancer from other illnesses. It was common to wait until more specific symptoms occurred before going to the doctor. For this reason cancer patients were cared for at home using various domestic cures based on folk medical practice, such as pressing the affected area with stones or drinking liquid prepared from birch ash. I demonstrated that domestic treatments were mainly used to soothe the complications caused by incurable cancer wounds or to charm away the growths from which patients suffered. People who had gained special healing powers, used their hands to cure cancer, however people avoided direct contact with others when they were sick, which again brought out the image of cancer as contagious, an image that many still have, at least according to the cancer narratives.

During the 20th century, along with rapid changes in the medical system, people's awareness of cancer increased a great deal. This has also influenced the image of cancer in popular discourse over the past

decades. From the medical point of view, cancer is a complex disease, so much so that some physicians claim every cancer should be seen as unique. Based on the cancer narratives, I would draw similar conclusions. However, it is more typical that in modern medical discourse cancer is approached as a simple cellular mutation causing changes in the body. This causes great differences in the ways in which ordinary people and professionals handle, and reason about, matters connected with cancer. From the scientific point of view there are still much that is unclear about cancer. This is a big problem as, according to culture-bound illness ideology, people falling ill need an explanation for the illness origin in order to better cope with the disease.

It is rather common in cancer narratives that people try to analyse the reasons that have led to cancer. It is important, therefore, to understand that for patients, cancer's rational explanations, given by physicians, are seen as mainly relating to the bodily experience, such as tests during follow-ups, surgery, chemical treatments, and the period of recovery; whereas the irrational meaning of cancer is often connected to human thinking and interpretation of the experienced events. This could be called a 'sense experience', which derives from the socio-historical context in which cancer is recognised as a particular 'evil being' with supernatural qualities. As in the past, when thinking of cancer today, people perceive images of an outside intruder or stranger who enters the human body in order to harm it.

The image of illness attacking from outside is so common that it could be one reason why people find it difficult to believe in all kinds of preventative techniques, such as quitting smoking, eating healthily or taking some more exercise. In terms of avoiding cancer, people appear to reason differently: it doesn't matter what you eat or how you take care of yourself, as long as your inner protective walls hold, you will be safe.

Characteristic to any set of popular beliefs, the ideas on cancer origin found in the analysed texts are heterogeneous and contradictory. Some of these ideas are guided by language, others are culture-bound and absorbed during the socialisation process. For example, in Finnish the name for cancer is *syöpä*, 'the eater', perceived as a worm-like being. Therefore, from the linguistic point of view, cancer can be described as a worm-like disease that is determined to destroy the body. In contrast to Finnish, many other languages call the illness cancer, also meaning crab, which creates rather different mental connotations.

In addition to the worm aetiology provided by language, several respondents define themselves as having a cancer personality. According to their writings they describe themselves as being weak and vulnerable, working too much, worrying too much and not taking care of themselves. Such an image of the cancer personality is pre-defined by boundaries set by our culture-bound knowledge, although the idea of the cancer personality derives from the early psychologists at the beginning of the 20th century. Although modern psychologist and psychiatrists have found no proof that personality or personal qualities affect cancer, cancer patients' narratives clearly show that if the illness is explained as the result of psychological or personal factors, it is difficult to acknowledge that only the technical modification of the body can heal the cancer. Furthermore, the lack of spiritual support from physicians is a general and often-discussed problem in cancer patients' writings.

Individual interpretations within linguistic and cultural frameworks

In cancer patients' writing, which are interpretative by character as any other act of self-expression, individual experience is compared with popular images and beliefs. The study conducted here shows that, although human reasoning is open to continuous interpretation, individual interpretations are likely to correct themselves through contact with surrounding culture and linguistic ideology. Such culture-bound ideas define popular cancer discourse and its characteristic features. This means that even if people deny some of the popular ideas, they still reproduce the beliefs in their writings. For example, respondents express their ideas about the origin of cancer and deny the possibility of having a cancer personality. Such consistency in cancer discourse helps us understand and describe what is going on, particularly when dealing with a large text corpus in which numerous accounts can be said to 'interact' with each other. More importantly, such intertextual interaction brings out the idea of pro-activeness hidden in popular thought, mediated as it is by various communicative means including written narratives. Thus, we have another reason to take illness narratives into serious consideration.

For a long time people were incapable of diagnosing cancer in its early stages, thus it was approached as an untreatable disease, mean-

ing that people who contracted it were going to die sooner rather than later. This certainly explains the lethal image of cancer in popular thinking. Furthermore, even in the 1960s and early 1970s, having cancer was considered so devastating a disease that medical professionals refused to reveal the true cause of illness to their patients. Being aware of developments in the past helps us to understand why some respondents to the writing competition despise the word 'cancer' so badly that they refused to use it in everyday communication, and even avoided it in their writing. The fact that people have avoided discussing cancer in the past points out another significant aspect of the disease. Namely, as cancer has been a taboo topic, the concept itself is also considered stigmatising, which certainly affects cancer patients' reasoning when they are diagnosed with cancer. At least for a brief moment, as demonstrated in chapter six, *The Moment of Diagnosis and Metaphoric Transformation*, the diagnosis of cancer causes people to lose their negotiated identity and their previously established place in society.

As this study has shown, to talk or not to talk about having cancer is an important issue in cancer patients' writing. In the long text examples that I have analysed, two respondents, Ruth and Hanna, decide not to talk about their illness. Ruth explains her behaviour as follows: she cannot hurt others by talking about her illness; instead she decides that if she is mean to everyone, no one will miss her when she passes away. However, her story reveals that hiding her illness makes her feel really miserable. After sharing her big secret with those close to her, she feels a lot better. The other respondent, Hanna, again, talks about her cancer to her closest relatives, and becomes angry when one relative shares this with the rest of the world. According to her writing, Hanna never tells her work colleagues about her illness. She is afraid that one of them might confront her with inconvenient questions about her health in unexpected situations. Both stories reproduce the idea that being diagnosed with cancer leads to death. Furthermore, Ruth and Hanna's writing, like many other narratives analysed in this work, clearly demonstrate that discussing cancer in public is problematic for many reasons.

The analysis of the cancer narratives highlights the significant silence in culture-bound cancer discourse, which 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 understanding of 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 my second research question: why do people write about their illness? Based on the cancer narratives, various culture-bound restrictions surrounding the subject become apparent, which 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.

Representations or reconstructions of lived experiences

The interpretation of written narrative is linked to popular ideas, lived experiences and their representations and reconstructions in written narratives. The materials used here show that one of the most common culture-bound ideas about cancer is cancer's direct connection to death in human reasoning. This connection comes from the past and forces people to avoid the subject in everyday discussions. Talking about life threatening illnesses and death may cause uneasiness between communicative parties, which means that cancer patients must find other ways to express themselves. Written self-expression, no doubt, offers a good possibility to share one's suppressed thoughts without being judged or labelled by others. This also explains the great interest towards the archival request regarding the collecting of cancer experiences. According to the co-letters the archive's request offered an additional path by which to express ideas that run against the culturally or socially agreed ideologies.

In their writing, rather unexpectedly, numerous participants had chosen to bring out the positive sides that the experience of having cancer had brought. In addition, 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 other things take place as well: people fall in love, graduate school, babies are born, new hobbies discovered or old ones regained, etc. Thus, the image of cancer may have relative significance in human life, particularly if compared to other threats that put people's lives in danger: "*Jo ekana päivänä ma*

keksin hyvän lohdutuslauseen: On sentään parempi kuulla, että sulla on syöpä kuin että sulla on AIDS”, “Already on the first day I came up with a good comfort slogan: ‘It is better to hear that you have cancer than AIDS.’” (087)

Respondents also seem to share the idea that life is a road trip that doesn’t last forever (*elämän mittainen matka*). This road-trip has a certain length in the human mind based on cultural understanding and personal expectation. When it finishes before the expected time, people are not able to accept it without crises. However, when the crisis is over many patients find that the length of life is not so important. More important is that they have lived a satisfactory life that provides precious experiences – both good and bad (313).

Writing is a good tool with which to express, analyse and interpret complicated personal situations, and therefore participating in the writing competition has a great therapeutic importance for respondents. One important task of the cancer narrative is to describe the individual’s cancer experience in order to remember, analyse and communicate the lived experience. The reconstructions presented in the narratives are dependent on the illness course as well as the narrative tendencies and respondents’ primary purposes for writing. This means that despite constantly recurring themes, cancer narratives are by no means identical. In my opinion, it is not beneficial to classify these texts by certain narrative tendencies, or by the myths they provide. To understand and appreciate the uniqueness of the stories seems far more useful. This of course makes the interpretation of written narratives particularly challenging.

Practical structuralism and evocative milieux as factors impacting on the archival request

The writing process is complicated because it forces authors to choose between relevant and irrelevant themes. In general, illness narratives follow the culturally agreed structure of the pathological drama or illness course. Therefore, I have used practical or descriptive structuralism to describe how the stories are composed, in order to highlight their responsive character. Normally the cancer narrative describes the events that occur when a person falls ill. Some narratives also include descriptions of pre-symptomatic conditions and the post-recovery period, depending on the course of the illness. However, as the cancer

narratives under study have been collected by archival request, the analysed narratives, unlike book-length pathographies, have a mainly ethnographic value. The lack of literary features does not diminish the cancer narrative's significance as research material. Respondents have written down and interpreted their illness experiences according to the open-ended questions posed by the organisers of the archival request. Thus the stories gain an evaluative character. Despite the structural similarity, some writings contains more evaluation than others, depending on the respondent's written self-expression skills and their authorial intentions and selected tendencies. Thus, the collected writings allow study of the cancer experience on the individual, cultural and societal level using the narrative approach, whereas the written form gives to cancer narratives a certain autonomic value when they are studied.

The autonomy of written texts allows the study of the external and internal meanings implied by authors within a thematically united text. However, when talking about cancer narratives, it is difficult to decide which of the authorial voicings belongs to the external, such as culture- and language-bound ideologies, and which to the internal or personal set of cancer-related ideas. Naturally, the respondents choose the intentions of their narratives, as well as setting the timeline necessary to make themselves understandable. In their stories writers evaluate the period before and after the diagnosis, and also examine their feelings in different temporally and spatially defined situations. Thus, a great part of the narrating or writing process is connected with imaginary dialogue between man and self. Nevertheless, when dealing with cancer patients' writing we cannot reject the idea that the stories also have a communicative value, representing an ongoing dialogue between other communicative parties and the particular evocative milieu involved. Thus, the descriptions of individual experiences are drawn upon 'responsive' understanding and reception, which above all is defined by the writing competition dealing with cancer patients' experiences; meaning that the author's personal voice is controlled by culture-bound expectations as well as the expectations of the organisers of the archival request.

The structural analysis of cancer narratives points out that hospital events gain a dominant role in cancer narratives. The stories reveal that the time spent in hospital is important because it leads to certain solutions in the cancer battle, but also because it is a process provided and controlled by society. For patients, the time spent in hospital rep-

resents a period in their lives when attachment to the self becomes loose because they are handled as people with limited rights.

Although people are convinced that a large part of the healing process is dependent on their individual decision making and self-help, somehow the events that take place in healthcare centres and cancer clinics appear to dominate the cancer narratives. This demonstrates that people have certain expectations from their writing. As the writing competition was organised in collaboration with cancer patients' organisations, the writers are careful about sharing the experiences they gained in hospital. I suggest they use their writing as a channel to discuss various aspects connected to doctors, hospital personnel, the treatments given as well as the socially supported medical system in general. In hospital the respondents were expected to be patient patients, and similarly, in their writing they are expected to share their minds: talk about their experiences in the hospital as well as psychological advice and support. I suggest that this is the main reason why cancer narratives contain lots of criticism of modern medicine and the ways people are handled in healthcare institutions. I would like to point out that this kind of criticism does indicate that there would be no gratitude towards the help provided. Rather the opposite, people who have received good care and understanding mention it in their writings, however, misunderstandings and lack of attention as individuals make people write longer stories as the archival request has given them an excellent opportunity to do so.

Patients' feelings and suppressed ideas revealed in metaphors and dreams

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 writings, although containing truthful events, follow certain narrative tendencies and authorial intentions that make the events described 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 must be pre-selected in order to become meaningful within a narrative.

Secondly, cancer narratives are thematic writings that, 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 have 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 allows the creation of sufficient arguments, as well as results, and with those hopefully generates ideas for further discussion.

Interpreting written narratives as wholes is a complicated task because of their idiosyncratic nature. This is connected to the fact that every time cancer occurs it is different, as are the narrative tendencies, intentions, and the self-expression skills of respondents. As analysing the whole stories is a complicated task the smaller narrative parts, both descriptive and narrative-like, gain more significance. This leads to the situation in which the researcher's interests take over the writer's interests. For the writer the various episodes are just building blocks to put together the whole in order to construct a narrative. For the researcher the possibility to compare different narratives and analyse the primary units within larger contexts, such as the intertextual universe constructed by the large text corpus, reveals the particular qualities of written narratives. Thus, not only the described events and experiences, but also the inner feelings and thoughts of respondents become significant objects of observation. Particularly because writing is an opportunity for self-expression, which helps to clear the mind and make complicated issues understandable. And, as cancer narratives reveal, people choose to write instead of speaking because, as cancer patients, they often are reinforcing the fact that cancer is a culturally stigmatised issue that should not be discussed in public.

When dealing with cancer narratives I have asked myself how people write about their thoughts, feelings and experiences. This was a question that made me study what I have called spontaneous accounts in cancer patients' writings: firstly, metaphors relating to falling ill; and secondly, dreams connected with the process of being ill. Apparently, in their writings, people go through their inner feelings and experiences gained in the past. Although their stories are reconstructions of past events, the multiple paths of self-expression present in written narratives have needed careful examination to understand their significance.

In order to illustrate the complexities present in understanding the role of metaphor, I have examined how metaphors work and what they do in particular situations. For an in-depth analysis I selected the moment of cancer diagnosis, which may be interpreted as the most crucial in the cancer experience as for many cancer patients it causes inner chaos and loss of self. This is the moment when people lose their negotiated identity and their previously established place within society. According to culture-bound reasoning the moment of diagnosis can be seen as a moment of transformation from an ordinary person into a cancer patient. I have noted that to describe the transformation into patient the associated inner chaos personal emotions become verbalised and expressed using metaphors. I suggest that these pictures words in the texts aim to recall embodied experience and the connection these have to reality in order to make individual feelings perceivable to others. I came to the following conclusions on this subject: firstly, metaphors function as a culture-bound key with which to make comprehensible individual emotions; secondly, metaphor, as a primary unit, contains the freedom to choose a suitable word order, as well as the requisite amount of emotion in order to mediate in pictures words the situation in which cancer sufferers find themselves; and thirdly, the poetic freedom present within metaphor is used when respondents construct their particular "work in miniature" and make it a part of their thematic writing.

Like metaphors, dreams and dream narratives may be interpreted as spontaneous accounts in cancer narratives. Omens, nightmares, or ameliorating dream imagery have individual value, although considering the whole text corpus dreams form a particular milieu in cancer narratives. In my work I suggest that through dreams the respondents deliver intimate situations that allow the discussion of themes

that would be considered marginal, according to linguistic ideology or culturally defined discourse in different speech situations. As with everyday communication, the whole process of communicating cancer-related issues is understood as marginal, and sometimes even covered by significant silence. Therefore, the function and meaning of dream accounts represented in the cancer patients' narratives becomes particularly significant. I point out that dreams and dream-like imagery are interpreted as events that gain meaning from everyday life, and particularly in connection with the illness process. There are many taboos related to discussing cancer and even subjects relating to it, whereas talking about dreams has been interpreted as an entertainment among most people. Apparently, this does not create uneasiness in other communicative parties, and people who go through emotionally difficult times may employ their significant dream experience repeatedly to talk about their fears and concerns. The fact that dreams become an important part of the cancer narrative is certainly because of their significance in everyday communication. Dream narratives allow patients to share their concerns and thus may help them through emotionally complicated periods.

The patients' narratives, composed of various structural segments, are reconstructions of self-negotiation and individual decision making during illness. In addition, such texts describe feelings that appear insignificant to modern medicine, overwhelmed as it is by medical technologies and concentrating only on dysfunctional tissue within 'diseased' bodies. In this way, cancer patients' writing gives access to the human side of cancer discourse, which combines medical knowledge with popular knowledge of cancer. However, because of their narrative value, representations of cancer experience can be like fairy tales, where the evil one is destroyed and the heroes and heroines continue living happily ever after. We, as receivers, are likely to believe this, however, we really do not know if this image of the happy survivor given in the narratives is entirely true, partly true, or is it just vivid imagination or wishful thinking. This characteristic feature of cancer narratives also leads to the suggestion that beyond the available, accessible, materials, something else may lie that remains undetected and undetectable.

WRITTEN CANCER NARRATIVES

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