

# 1. Cancer Patients' Writing and the Process of Selecting Research Materials

Finnish folklorists have, since the 19th century, enlisted the help of ordinary people with writing skills in order to collect and preserve various kinds of folk tradition. This kind of collecting of popular ideas on various topics is not very common in other countries, but in Finland the long tradition of organising various writing competitions in order to collect autobiographical reminiscences on a variety of sociocultural topics began in the 1930s and has continued ever since (Fingerroos & Peltonen 2006, 14–17, Latvala 2005, 24–33, Salmi-Niklander 2004, 37–38, Virtanen 1988, 47). Various calls for writing, mostly lead by open-ended questions, are therefore familiar to Finns and thus such competitions result in numerous responses from people describing their individual experiences via the medium of thematic writing.

The motivations for participating in such competitions vary from the participants' needs to share their individual experiences, to a pragmatic desire to win a prize. Traditionally, the best writing has been rewarded by the organising committees and the winners have received for compensation either money or books. Thus, it is not uncommon for participants to append their bank account numbers to their entries, whereas in case of cancer, perhaps because of this illnesses image in the particular cultural setting, the desire to win the prize has not led to the creation of imaginary stories and experiences.

Quite typically among the respondents are many people with broken souls who find themselves in life crises trying to organise their lives through writing (Pöysä 1997, 48–49). Indeed, illness, and in particular

falling ill with cancer, may be seen as a life crisis that forces people to reconsider their lives, and in this context writing functions as a therapeutic treatment (Bolton 1999, 13). When analysing the Finnish lumberjack tradition Jyrki Pöysä has pointed out that for some respondents the writing competitions becomes a path to explore their marginal position within society (Pöysä 1997, 49). For cancer patients, writing appears to be characteristic of the desire to represent the cancer experience in a more positive light and to reduce this marginal image (Couser 1997, 182), both as a response to the generally accepted ideas that having cancer is a *kärsimysnäytelmä* (passion), *hidas kuoleminen* (slow death) or *kuihtuminen* (shrinking). Most important, and separate from the various individual reasons for participating, is the fact that the great number of participants, along with the large number of responses, proves that the possibility to discuss and represent the cancer experience has been generally welcomed among the target group.

Illness narratives, autobiographical and biographical accounts of illness, are also known as (auto)pathographies. The term pathographies was coined in 1993 by Anne Hunsaker Hawkins in her book *Reconstructing Illness: Studies in Pathography* (Hawkins 1999). With this book a new literary genre was declared, which has since become the target for many scholars, mainly from the medical and sociological field. Rita Charon has called this approach a “new frame” for medicine, which should improve many of the insufficiencies in today’s medical care (Charon 2006, 6–10). Namely, the narrative based studies shed light on patients’ experiences, their fears, health beliefs, individual expectations and disappointments within modern medical discourse. Bringing into the light the patients’ point of view, which is often suppressed in the biomedical context, can thus be interpreted as a form of social control (Frank 1995, 97). Cancer narratives presented in this work have many aspects in common with pathographies or book-length illness stories; however, as these materials have been collected via archival request, their main value lays in their ethnographic point of view, which concentrates on describing an individual pathological drama and not so much on presenting the various autobiographical aspects that are more characteristic to pathographies (Hawkins 1999, 25–30). Thus, this thesis is an attempt to add an ethnographic value to patients’ writing. Cancer patients’ narratives, which could be seen as short pathographies from the generic point of view, present illness and its written representation as culturally and ideologically pre-

defined discourse influenced by various diachronic and synchronic developments.

With the long tradition of collecting thematic writing in Finland in mind, the folklorist Satu Apo has argued that thematic writing, as a manner of traditional self-expression, may be well accepted for folklore research (Apo 1995, 179). Until the 1980s, thematic writing was not seen as a suitable source for folklore studies in Finland. The main problem was that there was no suitable classification for this material, as the existing classifications were based on earlier research paradigms concerned with fairy tales and Kalevala metric poetry (Latvala 2005, 27). In the 1970s Finnish anthropologists and sociologists became more interested in autobiographies, and a decade later folklorists found a way to study the written (life) narratives that had been sent to the folklore archives (Fingerroos & Kurki 2008, 11–14, Fingerroos & Haanpää 2006, 26–30). Folklorists have come to the conclusion that life narratives dealing with different topics share people's individual ideas and cultural values and create a significant meeting point in the form of a culturally understandable narrative (Hatakka 2004, 172–173).

However, accepting thematic writings like this as suitable for study by folklorists did not solve the multiple problems connected with named sources. Like any other folkloristic source the various collected thematic writings have both positive and negative sides, which one should to be aware of when utilising these materials. Therefore, in the following pages, after presenting the main premises and research goals of the thesis, I introduce the general aims of data collection, observe the results of the writing competitions and argue about the main problems concerned with the interpretation of thematic narratives.

## **The premises and goals of the research**

My primary intention is to examine cancer narratives from the folkloristic point of view in order to find and compare popular ideas regarding cancer, both in the past and today. In general, the folkloristic approach refers to the study of people's attitudes and behaviour towards certain culture-bound traditions, and in this work the aim is to study cancer and its significance and images in the Finnish context. I analyse written cancer narratives by following the course of the pathological drama

in order to point out what it means to fall ill with cancer and how this life-threatening experience is perceived and expressed in written text.

Above all, the experience-based narratives dealing with cancer are approached as ethnographic sources that express patients' inner feelings and attitudes, both to being ill and to becoming well again. To approach cancer patients' ideas and reasoning in order to interpret them correctly I use multiple perspectives (see Chapter 2). This also means that I approach cancer patients' writing as containing thematic units, with certain beginnings and endings, characterising the illness course. At the same time I point out that such units consist of various segments of self-expression, such as descriptions of various milieux or primary narratives with different aims.

In addition to a narrative approach, the following study is ethnomedical, uniting popular health beliefs that derive from Finnish folk medicine, as well as those connected with alternative medicine and with the field of biomedicine dominant in the contemporary cultural context. Naturally, these fields contain their characteristic features. The concept of 'folk medicine' refers to understandings of health and illness that are based on a particular belief system. 'Alternative medicine' represents methods and therapies that derive from different times, cultures and traditions that have been adopted in a new cultural context. 'Biomedicine' is used to indicate the purely scientific, so-called evidence-based, medicine dominant in Finnish state-supported healthcare centres. In Finland the concepts of folk medicine and alternative medicine have often been interpreted as the same phenomenon: something that is in some form of opposition to biomedicine (Honko 1983, 34). Based on the studied narratives, and considering the ethnomedical approach, making such an opposition is meaningless. Cancer narratives demonstrate that even those who agree with public opinion – that compared to biomedicine, folk medicine and alternative medicine are useless hocus-pocus – employ in their writing popular ideas and beliefs that are mediated by language. Thus, such ideas and beliefs are culture specific, and therefore, according to my interpretation, have an ethnomedical character. I shall examine the human reasoning surrounding these contexts, because as the cancer narratives point out, in cases of illness an individual's ability to think and argue becomes the dominant weapon with which to help them through challenging times.

With this study I wish to draw the reader's attention to cancer's meaning in Finnish culture from the cancer patient's point of view. I begin by introducing cancer and its position before modernisation by using ethnomedical records. The comparison between older sources and the cancer narratives allows the suggestion that even today cancer may be approached as a modern mythological illness. People fear cancer as they fear AIDS, and quite typically it is connected with images of death and dying. Interestingly enough, despite its mythical image cancer has not become a topic for vivid stories and legends, as has AIDS (Goldstein 2004, 13–14). Rather, discussing and sharing the cancer experience has been interpreted as stigmatising and is thus obscured by significant silence (see Chapter 2). The still unexplained nature of cancer's origin is reflected in today's cancer prevention methods and in popular beliefs concerning its origin. For most people it is difficult to grasp the biomedical definition of cancer as being the result of a single cell mutation; it is far easier to imagine it as an outside 'intruder', 'set-off by an individual's nature or behaviour (see Chapter 5). The roots of such explanations lay in the history of medicine.

My study shows that for a long time cancer was diagnosable only visibly and manually. Typically, cancer was discovered in its late stages, occurring as an open wound or incurable lump in the body. Since medical discoveries and the development of new techniques, cancer has also become diagnosable in its early stages. This has led to a situation in which the cancer diagnosis may come as an unpleasant and, foremost, unexpected surprise before any 'normal' signs of illness, such as tiredness, fever or pain, have begun to disrupt the individual's daily activities. In such situations, the difference between being healthy and being ill is determined by modern medicine and not by the individual.

The available modern medical treatments, perhaps excluding surgical procedures, remain close to the peculiar healing methods offered in folk medicine a century ago. The main idea behind treatment has again radically changed. Folk medical healing aimed to balance a sick person's condition, either by the power of words or with different healing medicines and treatments. Biomedical treatments aim to destroy the mutant cells or stop their activities. Cancer narratives show that the primary idea of Hippocratic medicine, *primum non nocere*, often translated as 'first do no harm', is long abandoned in today's medicine.

Or put in other words, treatments make people truly ill and make them suffer: *Koin jatkohoidot vaikeampana kuin itse syöpädiagnoosin ja leikkauksen*. “The treatments that I got afterwards were for me harder to accept than the cancer diagnosis or the surgery.” (549) *Tunsin itseni terveeksi niin kauan, kunnes tehtiin radikaalileikkaus ja annettiin sädehoitoa. Silloin vasta aloin olla sairas, väsynyt muutaman vuoden*. “I felt myself healthy until the radical surgery and X-ray treatments. Then I became really ill, tired for many years.” (555) This is a really interesting situation from the ethnomedical point of view. The main criticism that biomedicine makes of other treatment types is that any treatment used to complement biomedical cures cause more harm than good. In pointing out this problem, I do not wish to justify or accuse, only to discuss. Analysing cancer narratives from the ethnomedical viewpoint is an attempt to present patients’ needs as well as their desire that at some point they again be treated and approached as individuals, people who are able to make decisions and, in collaboration with doctors, improve their own health.

In terms of generic finalisation, the structure of the cancer narrative is somewhat loose. However, despite this structural looseness, the culture-bound and socially supported expectations arising from popular belief become easily visible among the themes tackled within the texts studied here.

The thesis goes back and forth between the form and content of the writing competition narratives, using historical and societal insights to outline how cancer discourse is mediated by language and culture. The structural-descriptive examination of different segments in the cancer narratives is compiled in order to discover the culturally defined meaning within, but it also goes beyond these texts, which in everyday life influence individual reasoning, and which, in the current context have, to some extent, affected the process of written self-expression. This study of the interrelations between the external and internal aspects of the narratives is inspired by William Hanks’ suggestion that “utterances are part of social projects, not merely vehicles for expressing thoughts” (Hanks 1996, 168). As a matter of fact, Hanks’ statement has become a central argument for the narrative analysis presented in this work. To be aware of what is expressed we must examine how it is expressed and why a particular speech situation is given as it appears. In my opinion, questions, particularly how and why, help us to comprehend the individual’s situation and create the opportunity

to find answers to the most exciting question: What is going on? The need to understand has guided me throughout the process of studying and examining the available sources.

While becoming acquainted with the research materials, I approached cancer narratives as a resource that creates an intertextual universe in which single texts composed by different authors begin to communicate with each other. By doing so, I am inspired by the view of American linguist Walter J. Ong, who has suggested that any written text, once finished, becomes removed from its author, creating an independent discourse (Ong 2002, 80). Although I am aware that the experiences, thoughts, and feelings uttered in cancer narratives are the result of each author's cognition, interpretation, and verbalisation, in writing, these 'phases' become united, 'fixed' in a form of written text that created an autonomic discourse. Such autonomic discourse offers for the researcher an endless number of opportunities to examine and study the texts without including the author, with the text becoming the only source posing questions and providing answers. My attempt to exclude the authors fails because of my interest in the 'intended' aspects of these cancer narratives. Mikhael Bakhtin's suggestion that all narratives have a "responsive" character (Bakhtin 1981, 280) makes me look for segments in which the respondents (indirectly) communicate with different people and institutions, and also milieux, in order to express their various concerns regarding their illness experience.

Somewhat to my surprise, meaningful images relating to cancer occur in single words, metaphoric expressions, dream narratives and sometimes even in the intended silences within – or even beyond – the source materials. Cancer patients' thoughts, emotions, and experiences represented in written texts point out various connections between the form and the content mediating the meaning. Accordingly, instead of being purely ethnomedical, this study turns into a multi-level analysis of cancer discourse. It is worth emphasising that most of the topics handled in the cancer narratives can be described as spontaneous input within the narratives. I refer to the fact that the way respondents handle the concept of cancer, express their feelings on hearing the cancer diagnosis, analyse the reasons for falling ill, share their dreams, or chose to be silent, has nothing to do with the instructions given by the organisers of the writing competition. I am quite convinced that

only the large number of available texts gives the possibility to identify and focus on the somewhat unexpected aspects that occur.

The analysis of the temporal and spatial meeting points in the structural segments of the narratives demonstrates that the secondary narratives concentrate mainly on the pathological drama, briefly referring to the times before the illness was diagnosed and concluding with reference to life after treatment. In a similar way, to coincide with readers' expectations, the chapters in the thesis are organised to follow the culturally and socially acknowledged process of having cancer. This means presenting cancer from the moment of diagnosis up to the end of the experience, which, contrary to cultural expectation, is not necessarily a painful death. As many respondents to the writing competition do, I want to point out that for many cancer patients 'the end' (although it is difficult to define it accurately) of the cancer experience actually marks the beginning of a somewhat different life.

Before moving further, I wish once more to underline that the ideas and results that will be presented in this work are different from those presented in medical or sociological studies. The evidence in this work is the written narrative, and the conclusions are based on the intertextual discourse created by different writings. As I see it, the available material communicating the individual, collective and societal aspects of cancer at the same time defines the possible results. Through significant words, expressions, themes, and narrated events respondents expressed various issues relating to cancer. Thus, I observe the significance of cancer via multiple cancer-concerned events connected with different times and places.

### **The *Kun sairastuin syöpään* (when I fell ill with cancer) writing competition**

The *Kun sairastuin syöpään* ('when I fell ill with cancer') writing competition was announced on the 1st of May 1994 and lasted until the 30<sup>th</sup> of September 1994. The writing competition was organised by *Suomen Syöpäpotilaat ry* (the Finnish Cancer Patients' Association), *Suomen Syöpäyhdistys ry* (the Finnish Cancer Union), and *Suomalaisen Kirjallisuuden Seuran kansanrunousarkisto* (the Folklore Archive of the Finnish Literary Society). The main idea, as printed on the writing competition leaflet, was as follows (see original in Appendix 1):



Falling ill with a long-term or serious illness may change a person, as well as his or her daily life, in many ways. Fears relating to cancer also cause concern for the patient's friends and relatives. In order to survive, patients find that talking with other patients, sharing personal experiences relating to falling ill and living with an illness, proves useful. Writing down personal experiences may also be helpful in order to make clear one's ideas about illness and its influences on oneself and the surrounding environment.

The organisers pointed out their hope for personal and authentic results. All participants were asked to describe their experiences, thoughts and feelings as accurately as possible. Also the main aim of the writing competition was clearly stated:

The Finnish Cancer Patients' Association wishes to collect experiences and thoughts personally narrated by cancer patients. The idea is to select the best writing in order to make a book that will allow cancer patients and their relatives to share their ways of surviving the problems caused by the illness. Relatives and close friends are also welcome to participate in the writing competition. The writer may select a suitable heading for his or her writing.

In the competition proposal, the organisers asked the respondents to discuss the following themes:

- Tell us about the experiences and feelings caused by your cancer, as you experienced them.
- Explain how falling ill influenced your relationships with other people. How did family members, friends and work colleagues take your illness?
- Has the illness changed your self-image? If yes, explain how.
- Were you able to talk about your illness with others? Did you want to do so?
- How did you survive the crisis caused by illness?
- Who supported you? Who made you suffer the most? Why so?
- Explain how people at the hospital acted towards you as a person and a patient. Did you feel safe and did you get enough support and information?
- Will time heal? Do you hope that in time you will be able to adapt? Will life continue as it was before falling ill?
- How did you survive your illness?

Additionally, the organisers of the writing competition asked people to write down their name, profession, educational background, date and place of birth, current address and phone number. Or respondents could use a nickname if they wished. Respondents were asked if the writing, or parts of it, could be published if the personal data was changed. The entries were expected to be less than 50 pages long, written on one side of A4 paper with plenty of space on the left margin. Organisers also told respondents that the writing would not be returned, so they should make a copy.

People were encouraged to present personal experiences in a creative manner. For the winner, the organising committee offered 3000 Finnish Marks, for second place 2000 and for third 1000 (1 EURO = 6 FIM). Additionally, five 500 Mark prizes would be given to other randomly selected participants. The five members of the board deciding the winners consisted of a school rector, the chair of the literature archive, a medical doctor, a manager from the cancer association and a physiotherapist. The results were made public in November 1994. A book titled *Haaste elämältä: kokemuksia syövästä* (The Challenge of Life: The Cancer Experience), published in 1996 and edited by Päivi Hietanen and Juha Nirkko, contained a selection of the best writing with comments from experts.

The importance of carefully studying the instructions given to writers is central in understanding the aims of both the collectors and the participants. Although the first impression when reading the responses seems to be that people were rather independent of the questions posed, further examination shows that people were well aware of the organisers' expectations. In cases where the respondents followed their own personal and authentic ideas and thoughts, they were continuously unsure if the response fulfilled the expectations of the writing competition. This kind of imaginary connection created between the respondents and collectors has a strong impact on the final outcome and general status of the texts analysed. As I shall return to this question in the following chapters, I would like to draw attention to something else that appears significant in the discussion on cancer. Namely, in the instructions for the writing competition, the word *syöpä* (cancer, literally 'the eater') is used only twice if we exclude the names of cancer organisations and their publications. Rather, the instructions use the words "long-term" and "serious illness", or simply "illness". From my point of view it is difficult to decide if this was a

conscious or subconscious decision by the organisers. However, the analysed cancer narratives point to participants' anticipation of the word *syöpä* and problems with using it in their writings:

*Syöpä. Jo itse sanakin oli jotain niin kuvottavan inhottavaa kuin vain saatoin tietää. Suomeksi tuolle sairaudelle on keksitty todella hyvä nimi: jotain, joka tulee varkain ihmiseen ja kirjaimellisesti syö, hävittää ihmisen pois.*

The eater. Already the word itself was the most terrible and awful thing I knew. In Finnish they have given a really good name for that illness: something that secretly comes and enters the human and quite literally eats, destroys, the human being. (401)<sup>1</sup>

If the organisers' decision to avoid the word was subconscious, this would quite clearly show a culturally agreed fear of the word cancer.

## Becoming familiar with resources

The results of the writing competition were magnificent: altogether 672 cancer narratives – all in all 6384 pages – were received filled with experiences relating to cancer. Compared to other writing competitions organised at the same time, only a competition called *Työttömän tarina*, discussing unemployment (1992), received more answers (Laaksonen & Piela 1993, 10). The importance of this particular topic is explained by the fact that the beginning of the 1990s was marked by economic depression in Finland, in which many people lost their jobs. In order to contextualise the collected data and to gain a clear insight it is important to consider the political and economic circumstances of the time. After the industrial growth of the 1970s and 1980s, the beginning of 1990s was a period of economic crisis. The main reason behind this was the collapse of the Soviet Union, as 15–20% of Finnish export products were produced for the markets of their eastern neighbour, resulting in an economic crisis that was even worse than that after World War II. Unemployment rose to nearly 20% (Kiander & Vartia

<sup>1</sup> Here and elsewhere in this thesis I refer to the competition text examples only with archival number. The original texts as well as detailed information about the respondents may be gained from the Folklore Archive of the Finnish Literature Society. The extended archive references are also given at the end of this thesis.

1998) businesses went bankrupt and many people lost their incomes. This crisis influenced politics and culture, and caused depression and hopelessness across the whole nation. Having health problems in such social and economic circumstances added some difficulty to the personal illness experience and made it worth sharing.

In the following table I have listed the various writing competitions organised by the Folklore Archive at the Finnish Literary Society dealing with health and other medical issues (see Figure 1). The table indicates that in the history of writing competitions relating to health and medicine, only the ethnomedical questionnaire *Medica* (1964), and the personal experience stories about tuberculosis *Parantola* (1971), received more responses.

In the cancer narratives the impact of this period of depression is fresh in writers' minds. Presumably the period of economic and social crisis made society more open to the pressures and concerns of the individual. Because of cultural attitudes that are deeply tied with the fear of cancer in Finnish society, it is difficult to imagine that the writing competition would have been more successful earlier. The large number of respondents allows the suggestion that 1994 was exactly the right time to collect these cancer experiences, as members of this depressed society were ready to share their individual fears and suffering, making them more willing to talk about their cancer experiences as well.

As I worked through my resources I had to make some corrections to previously given information concerning the participants' gender division. My minor corrections are mainly the results of observations made on the content of the cancer narratives. These observations increased the number of male participants from 67 to 73 and the number of female participants from the 594 to 599 (Hietanen & Nirkko 1996, 7). The difference is understandable, as the statistic posed by Nirkko and Hietanen is based on the personal data added to cancer narratives. However, content analysis revealed that the sender, as given in the header of each narrative, sometimes only had the role of mediator, as the actual text was composed by someone else. Thus, the experiences described in the cancer narratives may actually belong to someone other than the name indicated in the archival reference. For example, if it was stated within a story that a sister had written down her brother's cancer experience and sent it to the archive (139), I listed the narrative as a male experience for further examination.

<b>Name of the writing competition</b>	<b>Year(s) of collecting</b>	<b>Responses received</b>
<i>Kansanlääkintään liittyviä kyselyjä</i> (Folk medicine questionnaire)	1950	608 units
<i>Lääkäri- ja muita kaskuja</i> (Jokes and tall tales about doctors)	1953	106 pages
<b><i>Medica</i></b> (Folk medicine)	<b>1964</b>	<b>8720 units, 957 respondents</b>
<b><i>Parantola</i></b> (Tuberculosis)	<b>1971</b>	<b>9000 pages, 350 respondents</b>
<i>Kansanlääkintä. Kansanparannuksen kilpakeräys</i> (Folk medicine)	1978	2500 pages, 397 respondents
<i>Apteekki</i> (Pharmacy)	1980	256 pages, 44 respondents
<i>Kuukautiskysely</i> (Menstruation)	1982	511 pages, 98 respondents
<i>Reumaperinne</i> (Rheumatism)	1991	2583 pages, 203 respondents
<b><i>Kun sairastuin syöpään</i></b> (When I fell ill with cancer)	<b>1994</b>	<b>6348 pages, 671 respondents</b>
<i>Hoitotyö</i> (Nursing)	1998	5658 pages, 169 respondents
<i>Vanhemman kuolema</i> (Parents' death)	2001	87 respondents
<i>Hammashoito</i> (Dental care)	2001–2002	1450 pages, 98 respondents
<i>Kansanlääkintä Pohjois-Karjalassa</i> (Folk medicine in northern Karelia)	2001–2002	114 respondents
<i>Lääkärintyö</i> (Doctor's work)	2004	1300 pages, 60 respondents

Figure 1. Writing competitions dealing with folk medicine, popular health and medicine

The gender division among participants means that the sample is dominated by female respondents (see Figure 2), which is characteristic to most of such archival calls. Altogether 89% of participants were female, a statistic that in itself gives certain information relevant to the discussion of cancer related themes. In recent years studies have emphasised the medicalisation of females in various contexts within Western medicine (Helman 2000, 114–118). However, this does not explain why women have been more active in sharing their cancer experiences. Based on societal norms and agreements women have historically been more engaged with all kinds of medical systems, from preventative to complementary and alternative treatments. In addition, the fields of self-healing and domestic healthcare are typically dominated by women. Although men may share this knowledge, it is usually women who carry out the preventative and curative practices that take care of all family members. As women are more engaged with health problems in the domestic sphere, and in other areas connected with health and popular healthcare, they generally gain more medical experience than men. Female dominance when it comes to sharing individual cancer experience is also observable on the Internet forum for Finnish cancer patients, in which women are far more active and involved than men. As women seem more interested in their health than men, the dominance of female participants may also have something to do with the survival rates of cancer patients as, among the contributors, are numerous women who have survived breast or gynaecological carcinomas.

The slight increase in the number of respondents compared to Hietanen and Nirkko's suggestion is caused by fact that some of the narratives received were composed by two or more people sharing different perspectives on the same situation. Making a division between such inputs was complicated as the techniques for composing the cancer narratives are multiple, particularly as the situations differ radically. For example, an account written in memoriam of a cancer patient may include the cancer patient's diary references, letters, or other notes, combined with photos and personal reminiscences from the person composing the story (406). Although, such a story gives two different insights to a situation, it must be viewed as single archival account. On the other hand, if two persons describe the same illness course from their personal points of view (086 and 087), both accounts may be analysed as two separate personal cancer narratives. Because, in addition to cancer patients, others, for example relatives and close

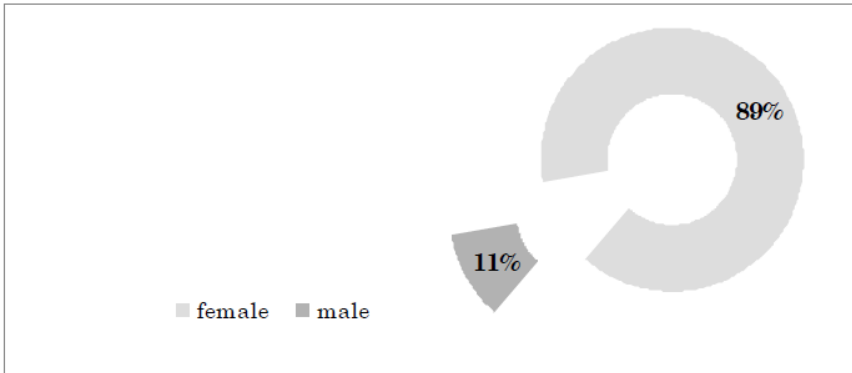


Figure 2. Gender division among writing competition participants

friends, contributed their thoughts and experiences, it is somewhat complicated to evaluate the data from the personal experience point of view. What I mean here is that the autobiographical value diminishes in such narratives and is replaced instead with detailed ethnographical descriptions concerning the lived experience.

It is rather common for the collected cancer narratives to include references to different cancer patients and their experiences. For example, a woman from central Finland analysed altogether 14 different cases of cancer experienced by her colleagues and friends (394). This raises an important question concerning the actual cancer experience. Does the experience belong to the cancer patient, or may anyone familiar with cancer and capable of composing a narrative be interpreted as having a personal cancer experience? I suggest that, compared to other accounts among the cancer narratives, those of personal experience are more profound because such stories concentrate on the important dialogue between the personal cancer experience and culturally accepted ideas, as well as social and societal practices. As the following figure shows, cancer patients' personal records (482 examples) form almost  $\frac{3}{4}$  of the available material (see Figure 3). For the sake of clarity I have excluded accounts that detail numerous other experiences in addition to the cancer experience, as in my opinion they contain significantly less value to this examination. In this work, however, I analyse the materials received from cancer patient's friends and relatives, as their secondary experiences include equally interesting data

in the ethnographic sense. Furthermore, the descriptions of death and dying in the cancer narratives analysed in the final chapter come only from the perspective of secondary observers.

The participants' profession was among the required information of the writing competition and quite obviously female dominance among the respondents affected the list of dominant professions. Accordingly, the most common occupations among the participants were teacher, office worker, and medical worker (physician, nurse, midwife). The cancer narratives also indicate that this same group of (lower middle-class) women is the largest sub-group within those who volunteer for various cancer patients' support projects, and this offers an additional reason for their great interest in this kind of writing competition. Among the male participants the profession-based distinction is more varied and without any clear peculiarity.

The age distinction among respondents was rather extensive as the youngest respondent was 12 and the oldest 98 years old. The most active writers were between 50–54 years and 70–74 years old. Among the writers were many retired people, who actively participate in all kinds of calls for writing. It is important to note that in cancer nar-

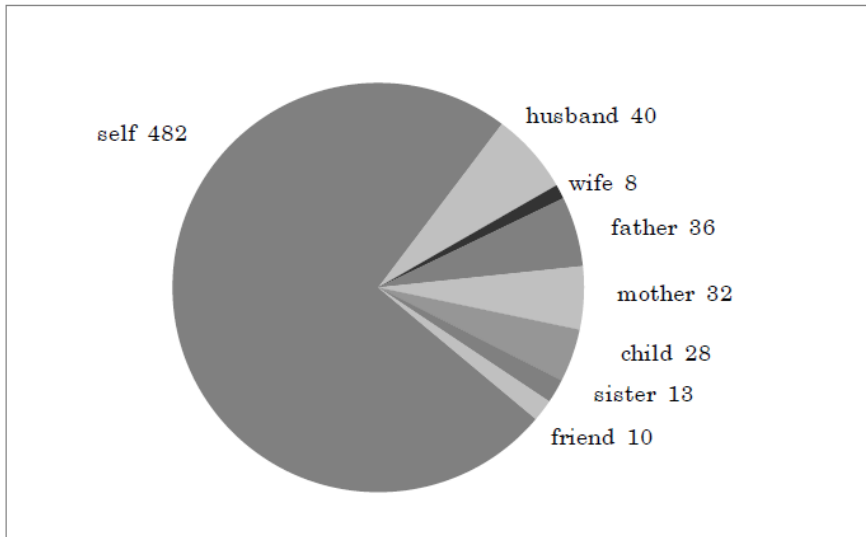


Figure 3. The main protagonist in cancer narratives



ratives the patients' age when falling ill has great significance. Often the cancer patients' ages when falling ill are explicitly expressed in cancer narratives. In cases where this data was missing I compared the required information and the information given in the texts (the year of falling ill). The following diagram (see Figure 4) represents my, to some extent rough, calculations of respondents' ages when becoming ill with cancer.

People have certain expectations regarding a 'normal' lifespan and therefore it is difficult to accept an illness that for some reason strikes "too early" (Finnish Cancer Registry, Statistics: incidence by age). Naturally, individual expectations of lifespan vary, although in the case of cancer it is understandable that the illness, with its killing image, is interpreted differently by patients of different ages. If a child, youth or young adult falls ill, it is seen as more unnatural compared to the diagnosis of cancer in someone more mature who has had a long and eventful life. In the cancer narratives analysed here people often question how cancer can attack children and young people. In this manner, a 15-year-old leukaemia patient wonders:

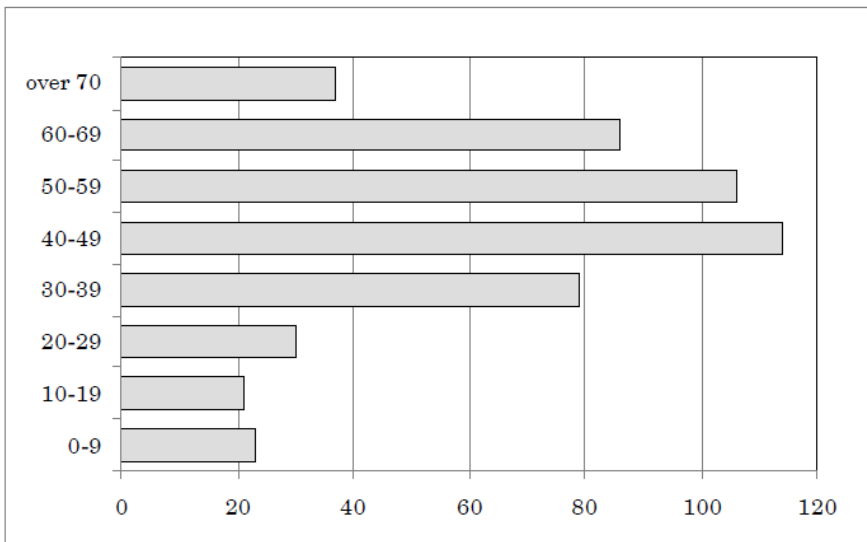


Figure 4. The age of falling ill

*Mä en oikeastaan tiennyt mitään ennen sairastumistani tästä kyseisestä sairaudesta. Oikeastaan mä luulin, että vain vahoilla ihmisillä on syöpä. En mun mieleen tullutkaan, että lapset vois sairastua siihen. Nykyään Suomessa sairastuu noin 150 lasta vuodessa syöpään.*

Actually I didn't know anything about this illness before falling ill. I actually believed that only old people have cancer. It didn't enter my mind that children could fall ill with it. Today in Finland about 150 children fall ill with cancer every year. (057)

The belief that cancer only threatens people in their old age is closely connected with medical history. In antiquity many observations were made regarding cancer, but for a long time cancer occurrences were connected with particular age and gender aspects of society. For example, in 1700 Italian physician Bernardino Ramazzini (1633–1714) noted that breast cancer is very common among nuns. Other cancer forms became diagnosable after studies with the microscopic, and pathology, developed. Finally, cell theory, developed by the German Rudolf Virchow (1821–1902), radically transformed the medical (micro-level) understanding of cancer (Porter 1999, 575). Typical to popular reasoning, such early ideas and discoveries affected health beliefs and so it is understandable that respondents emphasise the patients' age of illness.

Social studies have demonstrated that equality in health and healthcare has, generally speaking, been consistent despite political and economic problems in Finland (Kautto 2003, 3, Lahelma et al. 2001, 2–3). Although variation among different social groups is small, I would like to point out that general health behaviour in cities and villages, or small towns, has at least two significant differences that influence respondents' arguments concerning their illness experience. Furthermore, based on material at hand there also appear to be some meaningful dissimilarities between the healthcare offered in urban areas, and that offered in country areas.

The following map (see Figure 5) demonstrates roughly the places from where the writing competition entries originated. The map offers a general overview of the collected materials, and how these texts represent different parts of Finland. Unfortunately, the map does not mediate the accurate place of residence, the location where the cancer was discovered or where treatments were received. The map demonstrates that a large amount of material comes from urbanised areas of Finland. Helsinki city and the Uusimaa region are the most

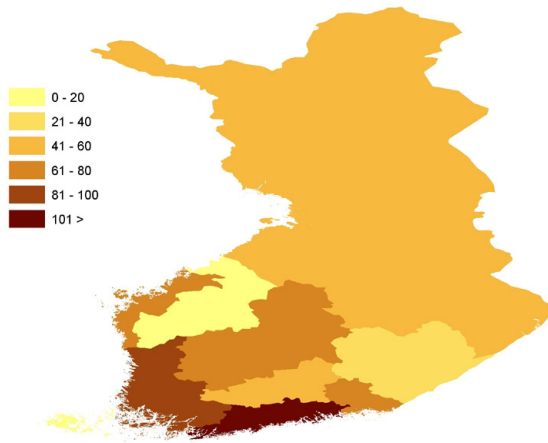


Figure 5. The participants' places of residence

intensively populated areas of Finland, and therefore it is not surprising that 23% of all respondents come from this region. The other two rather well represented areas are the Turku/Pori (Varsinais-Suomi, Satakunta) region and Tampere city and its surroundings (Häme, Pirkanmaa). Other areas of Finland are represented quite equally, except the eastern part (Mikkeli, Savonlinna, and Lappeenranta). Among the participants there were also four expatriate Finns, and four respondents did not add their address (although it was requested in the competition instructions). It is quite typical that the competition was more successful among people living in cities and small towns than among those living elsewhere.

Compared to similar writing competitions *Työttömän tarina* (1993) and *Maan sydämeltä* (1996–1997), organised by the Finnish Literary Society's Folklore Archive, the writing competition examined here shows few differences among the respondents' geographical origin. Perhaps the number of Swedish speaking Finns was higher than usual (*Käsikirjoitusten aineistoluettelo*).

This leads to the hypothesis that the idea of discussing the cancer experience is somewhat more accepted in urban areas than in the countryside, although the idea of hiding cancer from others seems

typical to cancer discourse in general. The principal change across time has been medical and public attitudes towards the discussion of cancer. People fear their illness and its outcome, but additionally they fear other people's reactions and behaviour as they hear about a diagnosis of cancer. Roy Porter, the author of the outstanding medical history *The Greatest Benefit to Mankind* (1997), has described cancer "as the modern disease par excellence that became the subject of terrible taboos, seen not just as fatal but as psychogenic, the product of a so-called 'cancer personality', the self that eats itself away through frustration and repressed anger" (Porter 1999, 574). Such personality bound myth has helped shape the secretive nature of cancer and made the disease in many societies unmentionable.

Cancer narratives indicate that several aspects of cancer and cancer patients' behaviour are dependent on a patients' place of residence (see Finnish Cancer Registry, Statistics: incidence by central hospital district). As I pointed out above, the dividing line is generally between country and urban communities. According to the materials analysed, a patient's geographical location within Finland affects their access to medical services and also their general attitude towards doctors and illness. In the cities people are forced to go from one doctor to another, getting lost in a tunnel of expertise. For example, one respondent described visiting 26 (125) and the other 43 (257) different medical professionals during the two years after being diagnose with cancer. In the countryside, on the other hand, people may undergo feelings of embarrassment and frustration, as the single available doctor is incapable or unwilling to diagnose the reasons for patients' tiredness and lack of energy as the early symptoms of cancer because of professional supremacy (048, 061). In both cases it is notable that people are unsatisfied with the way medical healthcare is organised and made accessible to ordinary people.

The other significant difference between urban and country communities is connected with the culturally stigmatising image of cancer. It appears that in the countryside people evaluate and reflect their experiences more through collective experience and are more influenced by the opinions and judgements of neighbours: "*Sehän on sensaatio meidän pienessä kylässä, kun sairastuin rintasyöpään*". "It is a sensation in our little village, that I fell ill with breast cancer." (398) Being surrounded by a local community may be experienced as supportive; however, in many cases it causes feelings of being misjudged and abandoned.

The cities dominate individual attitudes and norms of behaviour. In the urban context people may, at least to some extent, hide their illness from relatives, friends and work colleagues, or select with whom they share their illness experience (087, 465). This, however, makes them suffer from loneliness and a lack of support: "*Olen koko ikäni pelännyt tunteiden voimaa ja järkeistänyt kaiken. Olen liian hyvin sisäistänyt meidän itsehillintää ihannoivan kulttuurimme, jossa heikkoutta ja surua ei sovi näyttää*". "I have, all my life, been afraid of the power of feelings and kept everything reasonable. I have accepted our culture of admiring self-control, in which it is not proper to see weaknesses too well." (412) Moving towards analysing the everyday problems of cancer patients, I emphasise that social misjudgements towards cancer patients are one of the greatest challenges to all cancer patients, and therefore discussing this issue is highly important. In order to do so, I shall take this issue up later (see Chapter 5).

To describe the resources used in this thesis properly it is also important to define the dates of the events described in the cancer narratives. Although the writing competition was organised in 1994, the texts focus on various personal experiences representing different decades of the 20<sup>th</sup> century. A few of the personal experiences lead back to events that took place at the beginning of that century (001, 047,

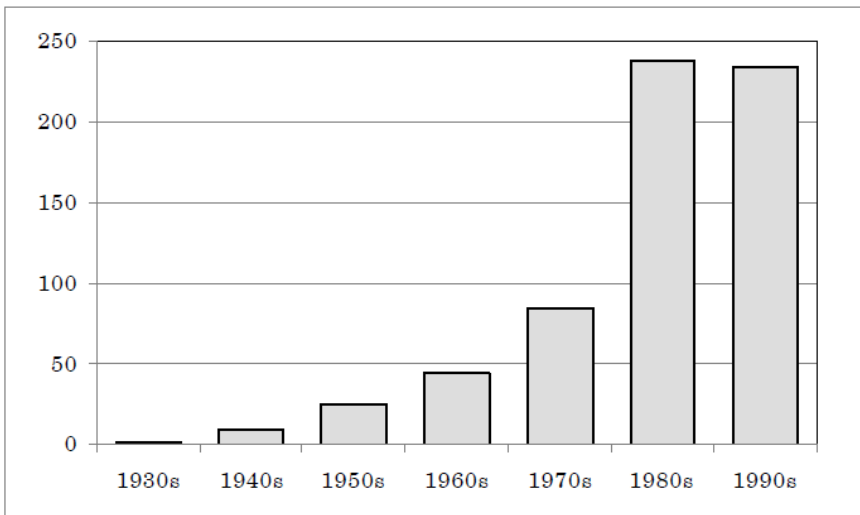


Figure 6. The dates of events described in cancer narratives

197). The majority of cancer narratives concentrate on events occurring during the second half of the 20<sup>th</sup> century, starting from the 1950s. Figure 6 indicates that the largest amount of material concentrates on experiences gained in the 1980s and the beginning of the 1990s.

This expanded timescale also influences the way that cancer narratives are written. The positive aspect to this is that the extended timescale allows observation of the developments in cultural attitudes towards cancer. Cancer patients who experienced cancer some time ago make useful remarks and observations in their writings about the differences between having cancer “then” and “now” (for example 590, 600, 608, 620, etc.) and their own experiences are often compared with those of their parents or relatives (586, 596, 601, 611).

For a long time cancer patients treated in healthcare centres were not aware of the name of their disease, and quite often the reason for their deaths was hidden from their relatives. As the following example demonstrates, the changes in attitudes towards discussing cancer with patients, and also in public, came in the 1980s and 1990s, and is still in progress today:

*Ei siihen aikaan puhuttu paljon syövästä, tokkopa aina tiedettiin kukaan kuolinsyytä. [1977] Tänä päivänä syövästä puhutaan, siitä tiedetään sitä tutkitaan, pyritään pääsemään mahdollisimman pienillä vauriolla, menetyksillä. Mammografia lienee tärkein anti naisille yhteiskunnan taholta. Toivoisi joukkotutkimusten lisääntyvän myös nuoremmille naisille. Vuonna 1986 ei syövästä paljon puhuttu, ei käytetty paljoakaan mammografiaa. Tuntuu, että se oli suorastaan kielletty paha puheenaihe.*

At that time [1977] people did not talk much about cancer, one hardly knew the reason of death. Today people discuss cancer, they study it, and try to cause as little harm and as few losses as possible. Mammography appears to be the best thing offered to women on behalf of society. I hope there will also be more screenings for younger women. In 1986 people did not talk about cancer much, they did not use mammography either. It seemed that it was almost a forbidden, ‘bad’, topic. (185)

The issue of dates in cancer narratives is complex because the 20<sup>th</sup> century has been full of social reforms. Changes have taken place in all areas. The development of the Finnish healthcare system has been very rapid considering that at the beginning of the 20<sup>th</sup> century most Finns still used different folk medical practises to treat even serious health concerns, which they did at home. At that time the few available

county doctors had to manage with limited resources, which meant that the local healer's skills were far more available to ordinary people than the expertise of a trained doctor (Naakka-Korhonen 1997, 108). Later, during the Second World War, governmental efforts centred on the daily survival of the nation. Thus, the active period of social reforms and the process of reorganising the healthcare system, linked with the building of centralised hospitals, began in the 1960s. Since then most serious illnesses have been taken care of in the hospitals and healthcare centres using the methods of evidence-based medicine or biomedicine.

The available biomedical cancer treatments have developed hand in hand with changes in the healthcare system. The treatments have been influenced by discoveries and developments concerning cancer. The dominant role of biomedicine in state supported healthcare centres has led to a situation in which the majority of Finns trust, and only use, the officially approved biomedical cures. The unfortunate truth in this situation is that despite the amount of money and the efforts of different research groups, the human understanding of cancer is still limited, and therefore the various treatments offered to cancer patients offer relief accompanied by serious side-effects, rather than a cure (Porter 1999, 577). Therefore, the crucial question is how much the change in the healthcare system and the advances in available treatments have actually shaped people's attitudes towards cancer. Through an historical insight into Finnish folk medicine, and the available cancer narratives, I shall return to this subject in this study where it touches upon various situations.

Official statistics about instances of cancer in Finland are available from 1953. Since then, medical institutions and practising physicians have been asked to inform *Suomen Syöpärekisteri* (the Finnish Cancer Registry) of all diagnosed and suspected cases of cancer. Since 1961 this has been compulsory (Finnish Cancer Registry). Markku Koskenvuo, professor of public health at the University of Helsinki, has listed the ten most common cancer types in Finland. Per 100 000 people the cancer death rates for men and women were as follows: lung cancer (89/13), gastric/stomach cancer (25/13), pancreatic cancer (19/15), breast cancer (0/27), colon cancer (15/13), prostate cancer (43/0), blood cancers (15/9), rectal cancer (12/7), lymphoid tissue cancers (11/7) and ovarian cancer (0/12). In his epidemiological insight *Kansantaudit – esiintyminen, riskitekijät ja tutkimusmenetelmät* (National diseases – statistics,

risks and research methodologies) Koskenvuo proposes that the most common cancer types form 70% of all cancers, while during the years between 1971 and 1991 deaths caused by cancers have diminished by almost 20% (Koskenvuo 1994, 43). Despite the improvements in cancer prevention, such as state supported screenings for certain age groups, etc., cancer is still a serious problem affecting human lives.

The available statistics give a good opportunity to evaluate the representativeness of the collected materials in terms of the most common cancer types, although according to my expertise in popular reasoning, the particular cancer type is of secondary significance. As I shall point out later in this thesis, unlike biomedicine the irrational concept of cancer typical to popular reasoning interprets every cancer as unique, while at the same time, and quite to the contrary, generalising all cancer types under one heading – ‘the eater’. However, I also presume that as this particular writing competition was organised in cooperation with cancer associations, the respondents tried to be accurate in giving medical details: *Toivon kuitenkin, että tämä luku on oikein, koska pyrin siihen, että tämä kertomukseni olisi lääketieteellisesti mahdollisimman luotettava!* “I hope this part is correct as I try to make my narrative medically as reliable as possible!” (060)

The participants’ attempts to be correct when sharing medical information (including the type of cancer) is connected with their primary idea, or even hope, that oncologists and other medical practitioners would examine their writing at some point.

In Figure 7, representing the qualities of available resources (see the List of Extended Archive References), only the cancer types that appeared more than twenty times in the text corpus are presented. More than ten texts were about prostate, pancreatic, kidney, thyroid and brain cancer, while there were less than ten texts about liver or bladder cancer in the corpus. In creating this diagram, I avoided using exact numbers as many of the stories do not explicitly mention what type of cancer was concerned. In several cases the patients also suffered from a recurrence of a previous cancer, which also means possible metastasis in different body parts. This explains why the category for various and unmentioned cancer types is so large.

The large number of records about breast and gynaecological cancer is well understandable when considering that female participants were more active than male. On the other hand, the large number of female cancer experiences is explainable by the fact that since the



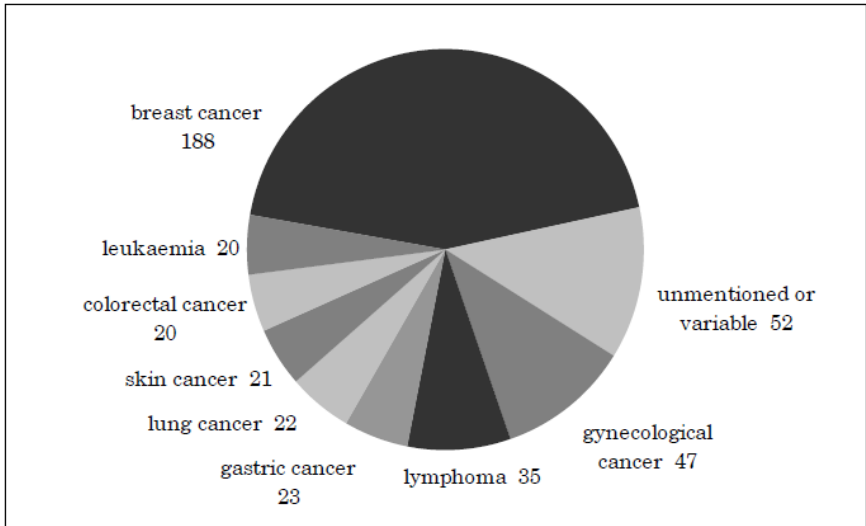


Figure 7. The most common cancer types in the cancer narratives

1970s, breast cancer particularly has been widely discussed in various mass media channels. I emphasise that this kind of open discussion has worked as an encouragement for the participants, and that open discussions have led to more competent controls, and accordingly an increase in the survival rates among female cancer patients.

The number of male participants in the writing competition was small. There were only ten records from sufferers of prostate cancer, even though prostate cancer has become the most common cancer among Finnish men in recent years (Matikainen 2001, 9). According to the Finnish Cancer registry 1586 new cases of prostate cancer were registered during the years 1989 to 1993. The number of new breast cancer cases among Finnish women was 2664 in the same period. Since I have followed cancer discussions intensively in the mass media, I am convinced that today men share their experiences concerning prostate cancer with less hesitation than they did in 1994, and it would seem that this is a very positive trend, one that highlights the importance of open discussion in coping with any disease.

All in all, the cancer narratives analysed do form a representative corpus: altogether 6384 pages filled with personal cancer experiences. The main advantage of resources like those used in this thesis, col-

lected via the writing competition, is that participants may share their lived experience from the personal perspective without fear of being evaluated as cancer patients. Of course, the participants of a writing competition are aware that their texts will be read and judged as writing, and they are influenced by the questions posed. However, during the writing process they are not affected by the influence of communication, as they are in daily discussions. This means that in thematic writing respondents may express themselves more openly, selecting more suitable and accurate words and expressions than in, for example, interview situations where the emphasis on communicative aspects is much higher. Performance-based narrative studies have shown that when being interviewed, people make strategic decisions and adapt their experiences, taking into account the performance context and the receiver's (interviewer's) expectations (Siikala 1990, 27–35). The benefit of written cancer narratives is that they have developed from the individual negotiation process. Because they are delivered in a written manner they represent a 'truer' version of events: the feelings, thoughts and experiences of participants offer multiple possibilities for textual interpretation.

### **Sources providing context: letters, ethnomedical records and Internet forums**

The reliability of sources may be increased by expanding the understanding of context. Therefore, I have selected some additional sources to augment the results of the writing competition. The letters are added to the original writing submitted to the competition and work as co-texts or metanarratives; they are particularly useful in understanding and interpreting the primary aims of the participants. The ethnomedical records, on the other hand, offer a diachronic insight into popular ideas relating to cancer before the modern healthcare system gained its dominant position in Finland. Additionally, the few cancer narratives collected from Estonia, and cancer patients' internet discussions, form a good grounding for comparative studies.

Respondents' letters, including personal data, remarks about the writing process and its meaning for the writer, form a very useful guide to context when analysing participants' perspectives as well as the writing process. In these co-texts, people explain and analyse the composed

cancer narratives, representing individual attitudes and challenges of writing down personal experience in the following manner:

*Oheisena on kirjoitukseni mieheni sairastumisesta syöpään ja hänen kuolemastaan ja niistä ajatuksista ja tuntemuksista, joita niinä vuosina mielessäni ja muiden läheisten mielissä liikkui. Jo viime syksynä mieheni elokuussa tapahtuneen kuoleman jälkeisessä mieleni kaaoksessa aloin kirjoittaa tuntojani selkeyttääkseni ajatuksiani. Se osoittautuikin hyväksi keinoksi, kun aloin koota palasiksi menneen elämäni paloja yhteen. Kirjoittaminen selvitti ajatuksiani, aloin osata elää yksinkin jatkaen sellaista, mitä olimme tehneet yhdessä ja alkaen jotain aivan uutta juuri alkaneessa elämäni vaiheessa. Tämän tietäen poikani toi minulle ilmoituksen tästä kirjoituskilpailusta. Mielelläni tartuin tilaisuuteen, tosin en niin kauhean mielelläni kilpaile, mutta ehkä minun kokemuksestani on jollekulle jotain hyötyä tähän niin kauhean ja niin yleistyvään sairauteen liittyen.*

I send you my writing about my husband's cancer and death, and about the thoughts and feelings that were in my head and in the heads of my close ones during these years. I began to write down my thoughts already last year in August when my husband died. I wrote down my feelings in order to clear my thoughts. It appeared to be a good method as I began to gather the pieces of his past life. Writing cleared my mind and I learned to live alone, continuing to do things that we had done together. I began even to hope for something completely new. Knowing this, my son brought me a notice about this writing competition. I accepted this gladly. Thus, I would not like to take part in the competition, but maybe my experience will be useful for someone concerning this terrible, and today so common, illness. (354)

*Mutta mutta. Kuten kaikki "kirjailijat" (anteeksi nimitys), minäkin aion kertoa ratkaisun sekä sen, miten siihen päästiin, vasta aivan kirjoitukseni loppupuolella, jotta jännitys (onkohan sellaista?) ei lopahtaisi liian aikaisin. [--] Nämä kysymykset ovat aivan ilmeisesti tarkoitettut ohjailemaan kilpailun osanottajia vastauksien laadinnassa. Tämä voi olla hyödyksikin, mutta minä en kuitenkaan voi muuta kuin kirjoittaa omalla tyylilläni.*

Well well. Like all 'writers' (forgive the name), I also aim to talk about the solution and how it was achieved in the final part of my writing, so that the excitement (if there is any?) would not stop too soon. [--] These questions are quite obviously meant to direct writing competition participants when composing their answers. This might be useful, but I can't help writing in my own style. (060)

The first example argues about the meaning of writing in order to express and clarify one's thoughts and feelings. The respondent also admires the idea of writing, although, she is not so excited about the idea of taking part in the competition. Like many other participants, she hopes that her writing might be useful and supportive for someone facing similar problems. The second co-text is quite interesting as it mediates the respondent's attitudes towards her own writing skills. In the letter she is quite ironic about her own attempts to compose an engaging plot, while also comparing herself with writers. She also points out that she could not follow the open-ended questions posed by the organisers, but instead wrote the story in her own style.

The co-letters also inform us of the participant's type as a respondent. In her book *Viinan voima* (The Power of Vodka), Satu Apo analysed the different types of respondent who participated in the sending of different folklore texts to the archive. Concerning these types, Apo has coined the term *kirjoittava kertoja* (the writing narrator). The writing narrator refers to a respondent who recalls and writes about his or her past; whereas a second type, *realistinen kaunokirjailija* (the realistic literate), refers to a person who makes an effort to give his or her text a literary value (Apo 2001, 17–18). I agree with Satu Apo in that, despite narrator types, the main value of such texts lays in their ethnographic significance. In the current case, the descriptions are of events connected to the processes of having cancer and ideas dealing with the subject. The extent of literary value does not change the quality of the text where that text is a fictive narrative. Because of the value of the writing, participants' letters form an excellent source with which to analyse and interpret the primary aims of the participants as they composed their personal experience narratives. Doing so plays an important role in answering criticism concerning the interpretation of the texts, which I shall discuss below.

Ethnomedical archive records form a good source with which to survey the position of cancer before and during the period of modernisation (see Chapter 3). These accounts help us to understand the changes and improvements relating to both the concept of cancer and the available treatments. I have utilised the ethnomedical records (*kan-sanlääkintäkortisto*) preserved in the Folklore Archive at the Finnish Literary Society to widen my understanding of the popular history of cancer. The ethnomedical materials were mainly collected during the second half of the 19<sup>th</sup> century and first half of the 20<sup>th</sup> century. Most

of the gathered texts are based on a questionnaire called *Taikanuotta eli opas taikojen kerääjille* (Magic Net: A Guide for the Collector of Magic). This questionnaire was first devised by the archive in 1885 and later edited several times (Naakka-Korhonen 1997, 80–81). In the collecting instructions people were encouraged to describe various health problems, among them cancer, from the following perspectives:

- *How was the disease created?*
  - *What kind of instruments, tricks and methods were used?*
  - *How could a person become ill?*
  - *What is the nature of this particular disease and how does it torture the ill person or animal?*
  - *What kind of intermediate instruments or magic tricks were used in order to cure the disease?*
  - *Why was this particular disease treated with these methods?*
- (Mustonen 1911, 38)

The collectors and informants were persuaded to give wider explanations about the reasons, symptoms, curative practices, and beliefs relating to various illnesses and diseases. Despite the questionnaire the ethnomedical records from the last decades of the 19<sup>th</sup> century and the beginning of the 20<sup>th</sup> century concentrate mainly on various folk medical treatments. In contrast to the cancer narratives, these texts rarely include personal experience accounts. Unlike other health problems recognised in an ethnomedical context, cancer has not created personal experience narratives, memorates or belief legends. Typically, informants describe the illness' origin and appropriate treatments very briefly, mainly because a lack of context makes the proper interpretation very complicated. Despite this lack of context, I found ethnomedical records an extremely useful source from which to gain historical insight into cancer discourse. Preserved ethnomedical texts form a unique source for the discussion and analysis of the curative practises used by cancer patients, as well as providing a way of analysing popular reasoning about the significance of cancer.

In 2005–2006 I made an attempt to organise a similar writing competition in Estonia, which, despite my efforts, resulted in only five responses. The material collected was extremely small, which made me consider the social circumstances in Finland in 1994 and compare them with the situation in Estonia in 2005 and 2006. The year 1994 came after a period of harsh economic crisis that affected everyone in Finland. A period, which I suggest made people more sympathetic

towards individual sorrows. In Estonia the years 2005 and 2006 were times of several economic and social reforms that affected people's welfare positively. This kind of radical period presumably left no place for the weak and diseased (for more, see *Minu vähihaigus*, <http://www.folklore.ee/era/kysitus/>).

While doing this research I have actively followed – and a few times under various names also participated in – the discussions on two Internet forums for Finnish (see Figure 8 *Syöpäjärjestöt*, [www.cancer.fi/keskustelut](http://www.cancer.fi/keskustelut)) and for Estonian (see Figure 9 *Vähifoorum*, [www.kaev.ee](http://www.kaev.ee)) cancer patients. One of my main interests here was finding out if, perhaps, the problems discussed in 1994 became less acute. In this sense, the Internet discussions have certainly verified that having cancer still causes identical human problems to those expressed in cancer narratives more than a decade ago.

The Internet forums were created in order to give cancer patients an opportunity to share individual thoughts with other cancer patients. The cancer narratives obtained through the writing competitions and the debates held in Internet forums are rather different from each other. Despite the fact that, in the cancer narratives, people tackle similar themes to the cancer forum participants, the latter is based on pressing questions and problems and offers active communication, and usually also immediate feedback. Cancer narratives are written in the hope of sharing individual experience and provide the opportunity for self-analysis in the critical situation caused by illness.

The reason I participated personally in Internet discussions was because of the pressing need to answer some research questions deriving from the materials analysed (see Chapter 5). I chose to participate in the discussions themselves only if I could not find a satisfactory answers from the forum or forum archive. When creating themes for discussion, my main aim was to search for some verification or extend the understanding of an ongoing problem. I must admit that the questions I posed did not cause active discussion. Typically I got few answers and it was not uncommon that the administrator of the forum was the only one who reacted to my problems or concerns. This work in the forums also confirmed that women are more open to discuss their problems than men, which ties in strongly with the gender division found in the writing competition participants. Despite the above, only partial, success, using the Internet as a source through which to extend my understanding of the materials at hand was an interesting experience and definitely worth doing in order to experience and understand how

The screenshot shows the website for Syöpäjärjestöt (Cancer Organizations). The main navigation bar includes links for Cancer.fi, Syöpä net-verkkokauppa, Neuvontahoitaja.fi, Seulonta.fi, and Syöpärekisteri.fi. A search bar is present with the text 'Yhdistykset ja säätiöt'. The main menu has categories like Etusivu, Tiedotteet, Järjestö, Tietoa syövästä, Syövän ehkäisy, Potilaat ja läheiset, Ammatillaiset, Lahoito, and Keskustelut (highlighted). The 'Keskustelut' section is active, showing a sidebar with links to Keskustelufoorumi, Vieraskirja, Sähköiset postikortit, and Voimaviesti. The main content area is titled 'Keskustelut' and contains text about the forum's purpose, registration, and navigation links like 'Elämäni ylläpitävältä lääkitykseltä elävät', 'Hoidot ja seuranta', and 'Lapsellani on syöpä'.

Figure 8. *Syöpäjärjestöt* www.cancer.fi/keskustelut [03.11.2010]Figure 9. *Vähifoorum* www.kaev.ee [03.11.2010]

The screenshot shows the Vähifoorum website. At the top, there is a logo of a red crab with the word 'KAEV' below it. The title is 'Vähifoorum' and the subtitle is 'Kõrbe teeb ilusaks see, et kusagil varjab ta kaevu (A.De Saint-Exupéry "Väike prints")'. There are several navigation links: KKK, Otsi, Liikmete nimekiri, Kasutajagrupid, Registreeri, Profil, and Privaatõnumite lugemiseks logi sisse. Below this, there is a table with columns: Alafoorum, Teemasid, Postitusi, and Viimane postitus. The table lists various forum topics and their statistics.

Alafoorum	Teemasid	Postitusi	Viimane postitus
<b>Üldfoorum</b>			
<b>Üldine</b> Foorumi kasutamisega seotud teemad - reeglid, kujundus, Kasutajagrupid, jne Moderaatorid <a href="#">Lopsalu</a> , <a href="#">Kersti</a>	6	23	Erm Juun 01, 2009 2:53 pm <a href="#">Krisuu</a> <a href="#">↕</a>
<b>Abiorganisatsioonid</b> Patsiendiorganisatsioonid, ametlikud esindusühingud, vajalikud kontaktandmed, jne Moderaator <a href="#">Kersti</a>	11	81	Teis Okt 12, 2010 8:07 pm <a href="#">Lilli</a> <a href="#">↕</a>
<b>Sotsiaalne toimetulek</b> Vähipatsiendi sotsiaalsed õigused ja -parandid. Sotsiaaltoetuste juriidilised, praktilised ja teoreetilised nüansid. Tööhõive ja suhted töösandjaga. Moderaator <a href="#">Kersti</a>	17	271	Erm Juun 20, 2010 9:33 am <a href="#">Krisuu</a> <a href="#">↕</a>
<b>Arutelud, kogemused, soovitusel</b> Kõik haigussega ja toimetulekuga seotud teemad Moderaator <a href="#">Kersti</a>	80	623	Helj Okt 14, 2010 10:34 am <a href="#">Sally</a> <a href="#">↕</a>
<b>Ühiringud</b> Veri, röntgen, kompuuter, ultraheli, mammograaf, jne Moderaator <a href="#">Kersti</a>	13	169	Reede Sept 24, 2010 12:43 pm <a href="#">Kersti</a> <a href="#">↕</a>
<b>Kes me oleme ja kust me tuleme?</b>			

such discussions function. Above all I have used these Internet forums for comparison and verification of my ideas and thoughts about the main concerns that cancer patients have (see Chapter 5), and also to cover culture-bound ideas that arise when discussing cancer patients' illness experiences and other concerns.

## **Approaching reliable results**

Written cancer narratives form a body of empirical data that is suitable for content or textual analysis. Traditionally content analysis is a research method that uses a set of procedures to make valid inferences from texts, with the main goal being the derivation of certain categories based on the available data (Weber 2004, 117). Content analysis, combined with other scientific approaches, is a widely explored method of interpretation in folkloristic research (Apo 1990, 62). However, other fields of research concerning human behaviour and reasoning have also employed such combined methods. In this vein, the Finnish scholar Veikko Pietilä has suggested that most fruitful content analyses use a collection of methods in order to assemble information from the research materials and to construct ideas (Pietilä 1976, 53–54, see also Uotinen 2008, 133–135). This means that, although content analysis makes selection through consideration of themes, paragraphs, sentences, words or expressions that appear frequently when examining the source materials, if required some aspects of content are explained in wider context. I agree with Apo and Pietilä's suggestions that although, historically, content analysis has been classified into qualitative and quantitative textual analysis, for successful and accurate results it is useful to adopt both methods, as it allows a more comprehensive description of the source materials. Thus, in the current study I shall adopt content analysis in order to become familiar with the texts created by cancer patients and to preselect the themes for further examination.

Approaching reliable results while manually selecting the subjects for further research is a complicated task. The tradition-bound demand for reality and truth of research results is a particularly delicate matter. In my view narrative based analysis should aim to be truthful and fulfil certain scientific criteria, although the request for reality or truth, whatever the accurate definition of these terms may be, stays



unachievable because 'the truth', as much as it is graspable, lies beyond any written data – it is 'written' only in people's minds.

The written texts preserved in archives are no longer directly connected to the events that took place in reality. As narrative representations, the preserved writings are in any case removed from 'true life' to a certain extent. The analysed cancer narratives represent the participants' interpretations of lived experiences. This interpretation means that participants' writing does not mediate the events that took place in life, but are a result of inner analysis, argument and selection in order to make the desired point. This means that, as the researcher, I am at least twice removed from the true events: the person who originally wrote down the information is once removed from the source, and the researcher is removed from the writer by another degree (Rosnow & Rosenthal 2005, 92). This is an important notion in terms of the request for reality or truth within any narrative-based research. Despite this, I trust that the careful examination and sufficient contextualisation of the available resources allows an understanding of the narrative representation from an objective background.

First of all, to add to the extent of objectivity the source materials must be carefully examined before making the selection for further research. It is necessary to become very familiar with the existing material, as ideas for studies often emerge from interaction between a researcher's substantive interests and his or her intimate knowledge of the information contained in the available sources (Kiecolt & Nathan 2004, 134). This is significant when clarifying several questions concerning the data: How is the data collected? What are the primary aims of the collectors? Who are the respondents? How are the texts produced? What kind of sociocultural backgrounds do the respondents have? What is the central message of the texts? I attempt to find answers to these questions, which relate to the information on respondents and the conditions that affected the creation of their cancer narratives. In the following paragraphs I shall describe and analyse my own decision making process as it relates to the selection of the materials for further research.

The original idea of organising the 1994 writing competition came from Päivi Hietanen, a Finnish oncologist working daily with cancer patients. I asked her about her aims for collecting cancer patients' experiences, and she said that she wanted some first-hand information that would help her to do her daily work. Similarly, in the text edition she has stated that a book version was published in order to

help and support people with similar problems, as well as to inform medical workers about cancer patients' experiences (Hietanen & Nirkko 1996, 7). When I studied the cancer narratives for the first time in the folklore archive, I had an excellent opportunity to question the second person closely connected with the original writing competition, archive researcher Juha Nirkko, who kindly explained to me the writing competition's primary ideas, the evaluation process, and mediated the feelings that the received texts evoked as they were gathered. This however did not stop me from creating my own ideas about the issues that these cancer narratives present. My background as a folklorist, and previous research interests relating to folk legends and folk medicine, made me focus on the character of the composed narratives and popular discourse on cancer as an illness.

In a way the whole text based interpretation process is dependent on a researcher's position. Laura Stark-Arola has written that intuition and prior knowledge play an important role in constructing hypotheses, and that the problem of intersubjectivity (how one's own presence and subjectivity influences analysis and interpretation) means that the researcher is less a discoverer or even interpreter of meaning than a maker of it, and that the role of his or her own culture-bound thought process must be acknowledged (Stark-Arola 1998, 67; see also Apo 2001, 37; Apo 1990, 77). Although the primary aim in the current study is to gain information about cancer patients' thoughts, experiences and feelings, one must agree that it is somewhat impossible to avoid intersubjective impressions; that is, the thoughts, feelings and experiences that the available resources create in me.

Source materials or texts are highly respected among folklorists, and therefore the materials and central question(s) concerning the interpretation of cultural phenomena often alter the research method(s) used. The concept 'text' is used as a metaphor for all sign systems of human making, and these systems contain meaning which can be "discovered", "read", or "decoded" (Stark-Arola 1998, 67). Thus, the preliminary assumption is that the events, thoughts and feelings described in cancer narratives offer an insight into the complex network of individual reasoning and socioculturally accepted norms and ideas relating to cancer. Dealing with texts means the researcher must aim to understand, or 'decode', the meaning of the available sources. Interpretation of written texts means that researchers give meaning and significance to words that are not originally theirs. In his book *Validity*

*in Interpretation* Eric Hirsch Jr. has claimed somewhat radically that, "since the meaning (parole) represented by a text is that of another, the interpreter can never be certain that his reading is correct" (Hirsch 1967, 235). Hirsch proposes that the researcher knows that the norms of language by themselves are far too broad to specify the particular meanings and emphases represented by the text. With this statement Hirsch argues that peculiar meanings specified by particular kinds of subjective acts on the part of the author remain in any case inaccessible.

I agree with Hirsch's assumption to a certain extent. As a folklorist interested in the processes of narrative self-expression, I am aware of various aspects that might influence oral communication as a written self-expression process. Compared to oral performance, the writing process is a subjective act of self-expression, filled with the writer's peculiar meanings. Furthermore it contains numerous rules and limitations set by cancer discourse as well as by the process of creating a written text. It is natural that as cancer narratives are constructed on the bases of individual experience of the illness process, the events presented in cancer narratives carry variable individual (primary) meanings and intentions. Somewhat characteristic to thematic writing is the fact that some parts of the received materials are written in order to describe, others to argue, and yet others to relate important thoughts or significant emotions. Nevertheless, the dominant intention among the writers appears to be the desire to communicate, describe the lived experience, and finally, make a point:

*Minun tarinani on tavallisen rintasyövän tarina, mikäli nyt ylipäätään syöpään sairastumista voidaan tavalliseksi sanoa. Siinä ei ole järjestytävää dramatiikkaa, kuten esimerkiksi huonoennusteisessa leukemiassa tai tapauksessa, jossa pienten lasten äidiltä löydetään yllättäen laajalle levinnyt nopeasti kuolemaan johtava syöpä. Mutta minkä sielun myrskyn tavallinenkin tapaus synnyttää! Kaikki muuttuu hetkessä, sillä sanalla syöpä on kuoleman kaiku. Mutta se on myöskin haaste, kutsu taisteluun elämän puolesta periksi antamatta.*

My story is an ordinary breast cancer story, if falling ill with cancer may be called ordinary. There is now appalling drama, like in the cases where the mother of small children is diagnosed with leukaemia or other widely spread carcinoma. However, the ordinary case may also cause a storm! Everything changes in a moment, as the word cancer echoes like death. But this is also a challenge, a challenge to fight for life without giving up. (428)

The cancer narrative is created with the aim of communicating something significant. Thus, the researcher's primary aim becomes understanding the meaning of a given text. Accordingly, the first time the researcher receives the spontaneous meanings is when reading and observing the texts. At this level the meanings of the received information are given by individual intuition, rules of understanding and sociocultural context (Siikala & Siikala 2005, 132–139). Observation then shifts from the intuitive level to the research level, which is affected by the existing text corpus, primary and secondary research questions and the methodological approach. As argued before, spontaneous meanings and individual cultural expectations add a certain amount of intersubjectivity to any work based on texts. This means that scholars interpret the sources according to their own experiences and sociocultural understanding, and so a respondent's meanings as expressed in text becomes newly interpreted and placed in an entirely different context, as defined by the selected research paradigm.

While reading and studying the materials at hand it was apparent that the writers' intentions were unclear and I felt the required tools for understanding were, somewhat, lost or hidden. This, however, did not make the whole thematic account meaningless, particularly within the framework of the thick text corpus. Despite numerous problems that limited accessibility to the writers' primary intentions, I suggest that studies based on a large text corpus offer an excellent opportunity to examine and reliably interpret the sociocultural images of any theme with particular significance. In this vein, the French philosopher Paul Ricoeur has emphasised that instead of being unclear, people want to be understood. Thus, writers use various methods in order to formulate their thoughts and express themselves in a comprehensible manner (Ricoeur 1974, 104–107). The words or expressions used by participants, as well as the primary meanings of the composed narratives, cannot have infinite ambiguity as otherwise the communication would fail (Lindqvist 1981, 25).

I emphasise that the texts under study may be approached as accounts intended to inform the reader. In this way the central ideas that are conveyed via thematic writing as a whole, in comparison to other kinds of narrative, take priority over the writer's primary intention, which is captured in the descriptive or narrative parts that are used to compose the thematic narrative. For both the reader and the researcher, thematic writing offers an opportunity to follow particular

culture-bound discourses containing respondents' central concerns as well as the impact of their experiences.

Satu Apo has proposed that written narratives create an inter-textual universe within certain contextual frames (Apo 1995, 139). I advocate that within these frames the participants are interested in sharing their knowledge and experience, which at first means respecting their 'voicings'. Voicings that may be concrete or metaphoric, but which lead to the researcher's interpretations within the selected methodological frames (Fingerroos & Kurki 2008, 14–15). As a researcher I am interested in studying the ethnographic information captured in cancer narratives, and even more in finding answers to the questions posed within the available methodological frameworks. Thus, my interpretation of the written texts does not denote finding the writers' primary intentions, rather that the foremost interpretation is a challenging multi-levelled task of building up a reliable contextual frameworks for the study of the multiple, culture-bound, meanings within cancer discourse.

### **Selecting materials for further discussion**

A researcher must analyse the content of his or her chosen texts to decide on the analytical units to be used, and this necessitates the selection of topics for further discussion. As I argued above, the selection process is mainly dependent on a researcher's choices and the research question(s) posed. In a way, the researcher creates a certain model that presents the research materials in a more limited and generalised mode (Pietilä 1976, 93; Wersig 1968, 14–15). In the textual analysis, the analytical unit may be the whole narrative, but may also be limited to significant words or expressions. Later the selected analytical units will be interpreted according to research question(s) and research method(s) presented at the beginning of each chapter.

Making the selection is partly an intuitive process (Apo 1995, 37) and therefore challenging to describe here. To start with, I examined the materials connected to organising the writing competition. After this I began to read and make notes about the available sources in order to extend my understanding of the information given in the materials. While reading and examining the texts I created a database that helped me to situate the available data. To extend my knowledge of

the materials and participants I wrote down, as accurately as possible, the following information:

1. Archive number of the source (from 1 to 671)
2. Page numbers in archive (1–6384)
3. Gender of the respondent (M/F)
4. Age and birth year (requested)
5. Education (requested)
6. Profession (requested)
7. Place of residence (requested)
8. Year or years of cancer experience
9. Age when becoming a cancer patient
10. The original cancer patient(s)
11. Cancer type(s)

To create the general database, I listed the most significant themes and possible further research topics in my research diary, which is helpful in recalling the whole interpretation process. In addition I made several files for reference on different themes, such as: medical personnel, oral history of cancer, dreams and predictions, the aetiology of cancer, meaningful tropes, writing and its significance, remedies, patients' roles, sexuality and physiological changes. In addition I made a reference file that was titled "to consider". This file included cancer patients' general notions about life, death and being a cancer patient.

The aim of such a careful analysis is to discover the general (most often repeated) constructions that derive from the primary content, themes and issues (Uotinen 2008, 142–143). Thus, my assumption is that the general constructions are connected to culture-bound ideas, and that this affect peoples' reasoning and decision making in everyday life, as well as when writing down their life-experience, the resulting texts having an ethnographic, and thus a primary, value for the folklorist.

The process of pre-selecting themes for this thesis was by no means easy as the short pathographies sometimes cover a participant's whole lifespan. The selection process could at best be described as handling the texts, at first with a horse-rake, then with a rake and then more carefully with a comb, without letting the whole field out of sight. Initially I picked out the three main themes tackled in this work: metaphoric expressions, dream narratives and accounts dealing with ethnomedical issues, such as personal illness aetiology and alternative

or complementary means of cure. At that point, I did not have an idea how, and in what context, I would interpret these accounts.

When reading the texts I also became interested in accounts that reflected respondents' ideas about their roles as cancer patients, both in the social context as well as in the medical. These textual units were bound with argumentation dealing with self-alteration and personal identity. As these topics are also connected with patients' bodily alterations and feelings (see Chapter 7), I made a methodological decision to avoid the current approach in social sciences that deals with the phenomenology of the body introduced by philosopher Maurice Merleau-Ponty (Merleau-Ponty 1962). This decision was based on my internal discussion as a folklorist, leading to the conclusion that, based on these pathographies, it is almost impossible to access patients' embodied memories accurately. In my view, written texts are interpretative by their nature and thus too far from embodied experience. As the question of embodied experience was not raised in the archival request, it felt too artificial to make statements in this direction.

I also asked myself several times what the meaning of illness is and how it is expressed in the pathographies under study. This question lead quite often to two further subjects: the general quality of life and death. I recognised the deep connection between the two concepts: cancer and death, and the carefully collected accounts dealing with death and dying. Despite patients' concerns regarding death and dying, the careful reading of cancer narratives also demonstrates that patients have a general need for reassurance and that there is life with, and after, cancer. Thus, although there is plenty of material dealing with cancer patients' concerns in this direction, I decided to select the issues dealing with living and being alive and re-thinking the meaning of illness in different situations for further research.

Apparently, rejecting some narratives and thematic issues is a part of the selection process. During the reading process I realised that some narratives and themes were more interesting for me than others. The more interesting themes are those connected with cultural expectation and popular thought about cancer. Some texts, on the other hand, were less valuable for the task of preparing this thesis. This was true of texts relating to the illness of children; equally problematic were long detailed descriptions of hospital procedures and stories that were too self-centred, describing only individual sorrow and suffering. After examining the texts I soon recognised that it would not be fruitful to

analyse them in my research as there were no answers to my primary research questions. Whatever other merits these texts may have, for my purposes they somewhat lacked the necessary context in relation to the cultural phenomena under investigation. I chose texts that allowed the requisite distance to be created for objective observation, without being either too emotional or too critical.

## **Problems with the presentation of the research results**

The content analysis that I employed to select the research materials for this work obliges the creation of certain generalised models in order to represent the results and argumentation of the research. Dealing with a text corpus based on the results of a writing competition creates several problems in this regard. In cancer narratives, the respondents' individual observations follow the psychological process of coping with serious illness and accepting the idea of having cancer. As I shall point out in the following chapters, for many people, adopting the cancer patients' role has a central significance. Compared to 'normal' life, the cancer patient's role means that individual decision making and personal life is abruptly interrupted. In their writing, participants describe how, by putting on hospital clothes, they loose control of their life and thus, for many respondents, the period of being a cancer patient and being treated in hospital signifies the unfortunate loss of personal identity. For cancer patients the crisis caused by their illness signifies a painful period of self-alteration. Thus, the central task of the cancer narrative is to describe the individual cancer experience in order to remember, analyse and communicate the lived experience. This means that despite constantly reappearing themes, cancer narratives are by no means identical.

On the other hand, in everyday life cancer patients are forced to fight popular expectations, like beliefs that being diagnosed with cancer equals fading and passing away. This means that, in addition to individual concerns, all participants emphasise in their responses culturally and socially important issues, showing that the respondents share 'truthful' information about the cultural meaning of cancer and its consequences. Regarding people who participate in writing competitions, Satu Apo has proposed that participants identify themselves as creators of scientifically valuable resources (Apo 2001, 19). Therefore,



despite the subjective experiences analysed in the writing, all respondents are aware of their role as the producers of ethnographically important material.

Cancer narratives form a large and heterogeneous text corpus, which at best suits the detection of different perspectives (Pöysä 2008, 238–240, Apo 2001, 17). Therefore, it is challenging to find the appropriate analytical categories with which to display both the individual concerns of cancer patients and culture-bound cancer discourse. On the subject of the themes discussed in this cancer narratives thesis, I do not wish to propose any cultural models of human illness behaviour as cognitive scientists have attempted (Holland & Quinn 1987). I am, above all, interested in tradition, which Lauri Honko has called “the stuff out of which cultures are made and which we have deposited in our folklore archives” (Honko 1988, 9). In the current context this refers to the ideas that people share (culture-bound cancer discourse) while analysing cancer’s significance in their lives.

The available materials create a certain space that becomes the model of culture, and the various connections that form the structure of this model are identical to traditional understanding of a particular situation (Lotman 2006, 78). In narrative based research this means carefully studying narrative structures, episodes, expressions and word use in order to understand what is expressed.

The culturally bound ideas deriving from and representing the cancer discourse are like any popular set of ideas that are heterogeneous and even contradictory. Quite often this means that in different texts the same ideas may be expressed and yet emphasise different things. Thus, the attempts to put such tradition into some kind of a model would end with one-sided, analytical categories that have no significance outside the particular study. Tuulikki Kurki has proposed that any analytical model represents only a researcher’s abstraction based on the source material (Kurki 1996, 23–24, see also Apo 2001, 28–31). This critical assumption suggests that it is difficult to aim for any scientifically accurate categories where culturally bound ideas and traditions are concerned. For the researcher, this gives the possibility only to read, compare and make comments when trying to map a particular tradition using his or her intuition. Such intuition-based study does not reduce the validity of research, but rather makes it more human (Hatakka 2004, 176). Hatakka’s statement regarding the human approach in interpreting written texts is crucial, because cancer

narratives exclusively reflect the participants need to be listened to, heard, and understood (see also Apo 1995, 37).

Considering the problem of modelling a large text corpus, Satu Apo and Veikko Pietilä have suggested that to support the researcher's arguments it is important to use sufficient examples (Apo 1990, 65; Pietilä 1976, 174). Using small text units as examples of participants' argumentation or personal 'voicing' has become a generally accepted method of qualitative content analysis, which I shall implement in this thesis. However, I point out that the main focus, when giving such examples as glimpses of general tendencies in the text corpus, must still be on the thematic whole and the contextual field that the particular unit derives from (Uotinen 2008, 141). As the whole narrative contains various textual dimensions (see Chapter 4) the single textual unit is inseparable from the general tendencies of the narrative. We must bear in mind that the general text corpus, with its values and characteristic features, also has significance in terms of understanding the aims and tendencies of the given examples.

In order to secure lasting contact between the original text and the text example, reference to the original texts must be accurate. This is also the reason why I use the original texts within the analysis, with English translations given in support only because this is an English language thesis. In fact, the translation of Finnish texts into English creates many problems. The sentences in the original texts are typically in the passive mode and thus difficult to understand for English-speaking readers. Additionally, when considering certain words and expressions, problems occur with different connotations. A prime example is the Finnish word *syöpä* (the eater) which demonstrates how one word may derive associations that are markedly different to the common English word 'cancer'. Therefore, the original Finnish quotes or expressions come ahead of their English translations.

The need to operate between complete texts and textual segments is influenced by Mikhail Bakhtin's suggestion regarding the understanding, or 'reading', of thematic narratives. Applying Bakhtin's ideas, cancer narratives (as wholes) represent the secondary (complex) speech genres that absorb the primary (simple) genres. In his study on speech genres Bakhtin has emphasised that, "if we aim to understand any essential system of ideas, or more precisely the nature of utterance, it should be revealed and defined by analysing both types of speech genres" (Bakhtin 1986, 61). Considering this notion, I begin this thesis by analysing the narratives as wholes before turning back to the

wider culture-bound context, then later moving further to analyse the primary genres employed in cancer narratives. The cancer narratives selected for textual analysis as wholes appear in chapter 4. I hope they give readers a good opportunity to compare my arguments with the ideas deriving from reading respondents' own writing.

## Evaluation of the available sources

On the one hand, thematic narratives mediate personal experience as the composed texts cover the significant events of individual life-history. On the other hand, such topic-centred (autobiographical) narratives form an excellent source for the study of socially and culturally defined discourse in a particular context. In recent years several Finnish scholars have proven that thematic writing dealing with personal experience is an excellent source for a folkloristic approach. For the particular scholarly approach that in Finland is called *muistietotutkimus*, the thematic narratives represent the results of historic and cultural processes merging with (secondary) knowledge and social activities (Fingerroos & Peltonen 2006, 12f.). Here, at the centre of the researchers' attention, is the communicative value of the text. It does not matter if the text is oral or written, what matters is what is told and how it is told, and perhaps one should not forget the aspects that stay untold for the same reasons. Accordingly, Ulla-Maija Peltonen has claimed that such text-based knowledge allows the acquisition of more information about historical and cultural variation regarding the construction of social reality and its interpretation (Peltonen 2006, 112). Regarding cancer patients' pathographies, this means the shedding of light on personal emotions, thoughts and experiences in order to challenge the official knowledge mediated by pathologies and statistics containing cancer survival rates.

In order to evaluate cancer narratives as research material, and to understand their communicative value, it is important to note that everyday events in human life cannot become narratives without cognition, interpretation, and meaningful references to personal experience. The German folklorist Albrecht Lehmann, who has since the 1980s studied *alltägliches erzählen* (everyday narration) among Germans, has introduced his theory on everyday narration as a path for *bewusstseinsanalyse* (consciousness analysis). In his book *Reden über Erfahrung* (2007) he used various approaches to point out that if we

discuss the narrative creation process it is impossible to differentiate between *erinnerung* (reminiscences) and fiction occurring in narratives. Considering the narratives analysed in this study, this is an essential statement. It points out that to evaluate the available materials it is important to examine the connections between experience, memorising, verbalisation and narration.

Lived experiences are by no means narratives on their own. Only through the verbalisation process is experience changed into narrative and accordingly the narrative becomes an act that breaks the silence on an individual level: due to narration personal experience becomes meaningful. Individually meaningful narratives have particular tendencies. To make his or her point a narrator must make a synopsis of events, even if he or she aims to compose a 'truthful' description of lived events. Despite the desire for accuracy, narrators are unable to express everything that has taken place in life. This also means that the reader of these texts cannot perceive the amount of untold events. The unverballed experience stays unapproachable, but to acknowledge this means accepting the idea of narratives as fictive representations of true events.

While studying thematic narratives it is important to have in mind that the process of composing a narrative is a thoroughly selective one, influenced by multiple frameworks, although the narrative as we first receive it seem to be mediating 'reality' (Apo 1995, 139–140). People select themes and issues that are important in the light of their personal cancer experience, but to be objective, they also search for words, expressions, themes and events that make a good and meaningful narrative. This is because people are familiar with the narrative schemata and general means of creating a narrative; however, not all people have qualities such as verbal expression or writing skills with which to create a coherent and perhaps even entertaining narrative, although archival requests demonstrate some demand relating to the literary qualities of collected texts, mainly by calling these activities writing competitions.

Folkloristic studies of narrative and narration have led to an understanding that in narrating, people firstly express experiences, values, concerns and ideas important to them as individuals or collectives, and, secondly, they do so through the employment of stylistic techniques, tropes, tones of voice and gestures (Klein 2006, 14; Kaivola-Bregenhøj 1996, 24–30; see also Stahl 1977, 17). Like oral performance, written self-expression is also influenced by an active selection making

process that is affected by individual ability to remember and verbalise the rules of written self-expression. This means that all available writing is affected by individual self-expression skills and the aims of the participant. As it appears in letters appended to the cancer narratives, the process of writing down individual experiences is by no means an easy one:

*Olen tässä kirjoittanut elämäni tosiasioita 7 vuoden ajalta, pörrötännyt niin kuin lankakerää. Kaikki vaiheet pysyy mielessäni elämän iltaan asti. Kirjoitusvirheitä on tullut, mutta ne kai annetaan anteeksi. Kirjoituskonetta ei minulla ole. Onpahan nyt asiat paperilla kynällä töherrettynä, jos näillä on jotain merkitystä jollekin...*

I have written about the life truths from the past seven years, spinning them as a yarn. All phases will stay in my mind until the end of my life. I have made writing mistakes, but I suppose they will be excused. I have no typewriter. I have smeared things onto the paper with pencil, hope they have some significance to someone... (267)

For folkloric study of narratives and narration, identifying the genre and its qualities is equally important for accurate interpretation. The American anthropologist William Hanks has suggested that “genres derive their thematic organisation from the interplay between systems of social value, linguistic conversation, and the world portrayed. They derive their particular reality from their relation to particular linguistic acts, of which they are both the products and the primary resources” (Hanks 1987, 671). In the current context it is significant that different illness narratives may have different culturally set qualities, mainly dependent on the particular discourse. Thus, to be interpreted according to the generic value emphasised by Hanks, narratives must gain a certain degree of ‘finalisation’ (Bakhtin 1986, 76). This means that if someone desires to share some significant aspect of his or her life, he or she must ‘fix’ the experience in the culturally appropriate model of narrative.

The degree of ‘finalisation’ characteristic to the cancer narrative is problematic as the extent of coherence, meaning, and emotional input in these narratives is foremost dependent on a participant’s skills in written self-expression. The majority of the analysed cancer narratives contain neither the “value of verbal art” (Bauman 1984, 30) nor the assessment of written, presumably poetic, literary text (Todorov 1977, 113). This lack of poetic or literary qualities or style is certainly not a fault. According to some researchers it an important aspect that tells its ‘readers’ that thematic writing concerning personal experi-

ence stands in between the oral and the written traditions (Apo 1995, 173–186; Peltonen 1996, 60–134, Pöysä 1997, 33–56, Salmi-Niklander 2004, 36–39). However, I do want to suggest that thematic writing should be seen as a unique genre with a specific written quality (see also Hatakka 2004, 173). Despite the lack of finalisation typical to oral or literary narratives, cancer narratives as thematic accounts may be approached as a whole that creates valuable context for use analysing the primary genres that occur within the texts (see Chapters 4, 6 and 9).

Considering human life, illness experience and everyday narration, Albrecht Lehmann has suggested that, unlike other illnesses, a heart attack or cancer signifies a borderline situation in personal life, and therefore narratives dealing with lethal illnesses differ from other illness narratives (Lehmann 2007, 198). The cancer narratives analysed in this work indicate that most typically the respondents examine their own life patterns after they became affected by cancer (Drakos 2006, 134f.). The times lived before appear less significant, and are discussed mainly in connection with the origin of the illness. Considering the material at hand, I would like to emphasise that even though ‘normal’ life (apparently) stops with the cancer diagnosis, individual lives continue to be full of everyday concerns and unexpected situations. One respondent rather wittily mentioned that: *”Ei syöpä kenestäkään enkeliä tee, ei ainakaan eläessään!”* “Cancer will not make you an angel, at least not as long as you stay alive!” (549) I find this brief notion is highly suitable to describe the amount of (thematic) variation present in cancer patients’ lives, of which cognition, reminiscence, verbalisation, and narrative composition process influence the quality of the final outcome.

# WRITTEN CANCER NARRATIVES

## An Ethnomedical Study of Cancer Patients' Thoughts, Emotions and Experiences

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