

ELORE (ISSN 1456-3010), vol. 17 – 2/2010.

Julkaisija: Suomen Kansantietouden Tutkijain Seura ry.

[[http://www.elore.fi/arkisto/2\\_10/paal\\_2\\_10.pdf](http://www.elore.fi/arkisto/2_10/paal_2_10.pdf)]



## **ILLNESS NARRATIVES: PATIENTS' ONLINE DISCUSSIONS ABOUT LIFE AFTER CANCER**

Piret Paal

According to sociocultural expectations, after cancer is removed or its spread stopped, people get a chance to continue with their daily lives. According to patients' experience, the return to 'normal life' after having cancer is full of challenges. During post-recovery, or the period that in cancer narratives is often signified as 'afterwards', people make attempts to return to their everyday activities, but are still confronted by medical follow-ups and the constant fear of cancer reoccurrence. Returning to normal life or 'the life before cancer' may be challenging if not impossible, as the surgeries and other cancer treatments are radical and leave their imprint in the body. Furthermore, the fact of having a life-threatening illness also makes people suffer psychologically. Based on written cancer narratives, which I have analysed in my doctoral thesis (Paal 2010), and online discussions analysed in this article, pain, tiredness, confusion and depression are daily companions for many cancer patients, who are, in the eyes of specialists, cured of their illness and should thus be, according to cultural expectations, healthy again and therefore act accordingly.

In this article I observe online discussions on a Finnish cancer forum<sup>1</sup> relating to patients' ideas about "life after cancer", which is also one of the forum's subtopics. I suggest that cancer patients compose their written narratives or share their illness experiences online in the hope of offering a different interpretation of the illness experience and thus confronting the culturally agreed image. The main motivation for sharing these personal stories of illness may be interpreted as the cancer patient's desire to receive some responsive understanding from other people, but also from institutions unfamiliar with cancer experience and its meaning on the individual level. According to Mikhail Bakhtin responsiveness in written texts exists, although "the orientation is not particularised in an independent act and not compositionally marked" (Bakhtin 1981, 280). Bearing Bakhtin's significant statement in mind, I have selected for examination three aspects relating to life after cancer : (1) when does life after cancer begin; (2) returning to work; and (3) having children after cancer treatments. The first question aims to draw readers' attention to a socio-culturally

defined borderline between being healthy and ill, which in case of cancer is dependent on medical expertise and decision making, but causes several problems for cancer patients (Paal 2009b, 49–51). The second question, returning to work, raises the question of societal challenge; accordingly, every healthy person should be capable of working after the illness is officially cured. And the third question concentrates on challenges in personal life course and the desire to carry on with life after cancer treatments. From the cultural point of view the need to be healthy in order to be able to work and have children can be approached as one of the greatest challenges of cancer patients. Namely, all these qualities play an important role in defining the personal identities as 'normal' in our societal setting.

#### NARRATIVE APPROACH: FROM BOOK-LENGTH PATHOGRAPHIES TO ONLINE LIFE-LOGS

Despite the fact that, according to official statistics, 80% of all cancer patients are cured today, in everyday communication cancer is often interpreted as an incurable and lethal disease, and thus understood and experienced as a direct threat to human life. The killing image of cancer deriving from past centuries and decades, the stigma caused by having a serious illness as well as cancer cures that attempt to stop the spread of mutant cells rather than heal the person, put cancer patients under pressure in various everyday situations. Thus, people are afraid or find it impossible to discuss their health problems with other communicative parties. As people are unable to communicate their doubts, fears and complaints, writing becomes an alternative path for self-expression.

Pathography is a relatively new literary genre, which deals with illness reconstruction and its representation from the patient's point of view (Hawkins 1999, 3–11). Over the past decades such book-length writing (alongside the growing criticism towards modern biomedicine) has gained immense popularity among ordinary people, which means that new books containing illness stories are published continuously. Because of the various levels of dialogic imagination<sup>3</sup> present in such writings, the pathographies tackle several important aspects connected to human life: everyday living, family and work, human relationships and other meaningful themes that have gained significance during the respondents' lives.

In a narrative self-expression a great part of the writing process is connected with an imaginary dialogue between the individual and the self. In a similar way to other forms of written illness narratives, such as diaries or letters, pathographies reveal patients' individual approaches, which draw on culturally agreed images of cancer. For example, some writers bring out the positive aspects that the experience of having cancer brought out in their personal lives. Rather often the lethal image of cancer is challenged by the examples based on individual experience, which is also understandable considering the number of patients who are eventually cured.

Written texts dealing with personal illness experience form a valuable source contributing to the study of various illnesses and their significance from the individual

perspective. Nevertheless, when dealing with such writings, we cannot reject the idea that the stories also have a communicative value, representing an ongoing dialogue between other communicative parties and the particular evocative milieu involved. Typically, evocative milieu in illness narratives is descriptions and stories of natural, everyday or hospital surroundings, which contain personal reminiscences, experiences and interpretations making the presented narratives meaningful (Paal 2010, 148–151). Furthermore, the descriptions of individual experiences draw upon certain responsiveness and reception, which are, above all, defined by the writings that deal with writers' experiences, meaning that the author's personal voice is controlled by culture-bound expectations as well as the expectations of the potential reader(s).

Modern media channels provide potential opportunities for the expression of individual thoughts, emotions and experiences connected to illnesses in forms other than books, diaries or letters. Internet pages and weblogs dedicated to personal illness experiences shed light on the course of individual illnesses, physical suffering and other pressing issues. This kind of online publishing could be defined as an action that is strongly linked to the tradition of writing illness narratives or even illness (auto)biographies (Lehmann 2007). In addition, life-publishing or life-logs<sup>3</sup> in virtual locations such as IRC-Galleria, Facebook or Twitter occasionally provide short written texts regarding personal health. Like pathographies, short health-related life-logs are written in the hope of sharing individual experience and providing the opportunity for self-analysis in the critical situation caused by illness.

Online life-publishing is a complex form of self-expression, which, additionally to words, may also contain pictures, videos and other means of hypertext. However, as we focus on language and discourse analysis of the text provided online<sup>4</sup> and compare them to pathographies, the writers' expectations towards responsive understanding remain the same in life-logs, which could therefore be approached as the smallest possible accounts of illness narratives. Susan Herring sees Internet life-publishing as a bridge between different genres, uniting writing styles from diaries, columns and reportage (Herring et.al. 2005, 142–171), which means that the information provided contains intimate details, argumentation, and also criticism towards the individual's socio-cultural situation and institutional decision making. The information provided via various genres of online publishing may be seen as particularly useful in understanding patients' expectations and concerns – the ones that should consequently lead to better care provided by professionals and the institutions providing medical help. Therefore, not only pathographies that cast light on the patients' point of view, which is often suppressed in the biomedical context (Frank 1995, 97), but also illness accounts published online can thus be interpreted as a form of powerful social control.

## CANCER PATIENTS' ONLINE FORUM

During my research on Finnish cancer patients' written narratives (Paal 2010) I actively followed the discussions on Internet forums for cancer patients. Such online forums are created mainly to give cancer patients an opportunity to share individual thoughts with other people in similar situations. Online discussion forums offer an opportunity to share personal problems, ask questions and help others.

Above all, I have used these online forums for the comparison and verification of my ideas and thoughts about the main concerns of cancer patients, and also to cover culture-bound ideas when discussing cancer patients' illness experiences and other concerns. It appeared that discussions on Internet forums are to some extent different from cancer patients' writings, although people tackle similar themes. Partly the difference between online discussions on cancer forums and illness narratives is based on pressing issues and problems, which offer active communication and normally also some (immediate) feedback. In my opinion the main difference between the cancer patients' writings composed on archival request and the online texts available is that the latter ones are never finished. Namely, the online context allows continuous additions, numerous returns to the subjects discussed already, and publishing new interpretations of gained experiences, which certainly also affect the mediated meanings and their correct interpretation (Kõiva 2010: 220-223; see also Kõiva 2009). Furthermore, some differences lay in the fact that the online discussion boards created to support cancer patients are hosted by cancer patient support organisations, which unite "every actor in comprehensive cancer control [...], bringing together scientists, clinicians, decision-makers, financial experts, volunteer helpers and patients"<sup>5</sup>, and dominantly represent the opinions of biomedicine. I suggest that the role of cancer patients' support organization as a representative of institutionalised and socially supported medicine limits the sharing of health myths or popular beliefs in patients' discussions to a certain extent; however, it does not stop people from sharing individual thoughts, emotions and experiences with those in similar situations.

The themes tackled on Finnish cancer patients' online forums are divided into fourteen main categories<sup>6</sup>. An updated discussion forum was established in 2007 and all older discussions were preserved in the online archive, which is also available for all forum users. Since 2007 'the life after cancer' category that I have selected for closer examination has had approximately 150 sub-themes posted for further discussion. However, some themes keep reappearing. Among the most actively discussed themes are: (1) returning to work; (2) life quality after cancer treatments; (3) fear of cancer reoccurrence; (4) depression; (5) reconstruction of breasts; and (6) having children after cancer treatments. Most certainly, the bodily and spiritual concerns of cancer patients should not be overlooked, but these problems can be solved by medicine or psychology. However, as already mentioned above, the questions dealing with drawing the line between illness and health and trying to get back 'normal life' lost while being ill are fascinating themes from the cultural point of view and there-

fore worth closer examination.

It is interesting to note that not all posts receive answers, and sometimes the responses come rather slowly, expanding over a long period of time. I suggest that the main reason for unanswered posts is connected with the fact that the same theme or question has already been posted by someone else in the past and the participants do not feel like repeating themselves. This means that new participants are expected to carefully read the older posts before setting up new themes for discussion. In addition, the requests from various researchers to share cancer experiences or information posted by the site administrator stay, as a rule, unattended. This highlights the fact that the people who attend these online discussions look mainly for advice and support from those who have experienced similar events and feelings themselves.

The studies have shown that in order to become 'heard' and understood by others in online discussions, people have to create a believable online-character for themselves by selecting a name and composing a text, which presents them as a trustable person (Jahn 2000, 375–387). As the matters discussed on cancer patients' forums are really delicate, people instinctively avoid contacts with those who post ignorant, inconvenient or impolite comments, or who talk too much. On the other hand, the streaming of all online content on the Finnish cancer patients' online forum demonstrates that the amount of active participants is rather limited, which is due to the fact that, in order to post a question or share personal experiences, people need to obtain a username and a password to log in, whereas to read the posts, a login is not required. This kind of policy keeps away unwanted guests or comments and certainly raises the level of reliability among the active participants.

Undoubtedly, using online materials is somewhat problematic as it raises an ethical question in terms of protecting the privacy of parties involved. As already mentioned, to join the discussion board under examination, people need to register in order to be able to share their thoughts and experiences, whereas, following the forum, i.e., reading the life-logs on the discussion board, is accessible to everyone, which is also clearly expressed while signing up as an active user. Thus, participants are informed that everyone can read their published stories. Participants' privacy, however, is well protected. While sharing their experiences or commenting on others' stories, the participants appear under their usernames, which makes their true identities hardly definable for non-registered users or those, who do not visit the discussion board regularly. Thus, patients' life-logs within the discourse of the discussion board consisting of multi-levelled text-chains gain an autonomic value separated from their original author. The online publications represent the ideas of online-characters, which visibly lessens the fear of revealing too much about the real persons<sup>7</sup>.

## HOW TO READ ILLNESS NARRATIVES?

In the sense of self-expression, interpreted here as an intended social speech act, the question of how to read the available texts is very important. In addition to the

psychological and constructive value fixed in the writing process, the importance of illness stories derives from their status as a source sharing attitudes and ideas about cancer. Thus, the illness narratives presented in the form of a written text add a multitude of voices important in comprehending the central question of this article: How to get back one's life after cancer?

In my doctoral thesis (Paal 2010) I argue that individual cancer experience is determined by temporal and spatial factors within a certain context, as mediated by written texts. To understand this, we must be aware of the context as defined by the dialogism between socio-historical development and socio-cultural discourse, i.e., the history of cancer and its consequences in the past and present. If the context that contextualises the text (narrative) becomes defined, it is easier to concentrate on analysing the episodes or accounts that mediate significant events and activities. Thus, understanding the schematic structure of a narrative (Labov 2004, 31–43) and its compositional parts leads to a better understanding of the meanings fixed in the text.

From the stylistic point of view online texts posted on the cancer forum stand between the oral and written tradition of self-expression. Although presented in written form, the literary quality of the text is not really important for most participants. Narratives presented in online discussions, similarly to many cancer narratives collected via archival request, are definable as “literary but extra-artistic authorial speech” (Bakhtin 1981, 262). This extra-artistic character refers to the general lack of literary value, which does not diminish the value of these entries as a form of social control, while these texts, as stated above, allow the study of cancer experience from various perspectives. However, when dealing with online materials, we must understand that these texts follow a style and rules of their own. For example, the life-logs containing personal illness experiences can be really emotional, making us sense the feelings involved without building up an entertaining plot. Instead of being more accurate in self-expression, people use gaps “...”, multiple exclamation marks “!!!!”, smileys “:-)” or capital letters in their stories, which are not considered common to literary texts.

*It is 18 months since the surgery and the beginning of treatments. My wife told me in the autumn that we should make a baby, as she is younger than I am. Well, I asked if there were any problems with it...*

*And what a weird thing! THEY HAD FORGOTTEN TO TELL ME BEFORE THE X-RAY TREATMENTS THAT I COULD BE STERILE AFTER THAT. I have not got over it yet. The possibility is really small; meaning that I am more likely sterile than there are any swimmers left.*

*I am so pissed off. I must gather some strength before I start the fight about the treatment mistake. There would have been no delay in my treatments if they had given me a little cup to give some samples for later use...*

Piret Paal: Illness narratives

*But no one thought about it before the treatments....*

*I am really angry...*

*Keeko | 13.11.2008 at 15:30:33*

During online discussions people form more or less coherent narratives in order to discuss their problems and concerns. In search of better communication, people compose their individual stories in accordance with traditional or national norms of written utterances (Bakhtin 1986, 65). This means that writers do not share all the inner concerns that might have affected them during their illness period. When writing, they activate their episodic memory and recall past events and episodes that evoke strong feelings and new ideas.

I have argued that, while composing their illness stories, the recalled events and episodes become interpreted and will be altered according to the social norms and rules that govern the production of a fixed narrative. The writer must consider the rules of performance (written self-expression), soci(et)al expectations (readers) and the general social and cultural context (discourse). Although people follow individual narrative patterns, depending on how they have been affected by their personal experience, the written narrative becomes evaluated through the cultural understanding of successful writing (communication). That leads to writers making choices on structural, vocabulary and expressional levels, and therefore people construct their narratives based on their own writing skills, which are constantly being compared with the individual's image of a meaningful narrative (Paal 2010, 79).

Accordingly, narrative composition as a course of multiple choices is influenced by numerous internal and external aspects. Firstly, the individual "verbalisation" or "textualization" process is affected by the individual's ability to memorise and remember (Lehmann 2007, 50–57). Secondly, people select the events and episodes from among a vast range of possibilities in the flow of experience and then present them in an order which itself, intentionally or unintentionally, conveys significance (Garro & Mattingly 2000, 260). Thirdly, narratives as representations always contain some kind of particular goal, and carry certain culturally defined functions as well as individual intentions affected by the context (Paal 2010, 64). Thus, in addition to the individual and socio-cultural aspects connected with the image of cancer, the rules of online publishing<sup>8</sup> affect the construction of personal illness accounts. Consequently, the online content, consisting of various forms of speech acts representing stylistic features of online writings, forms a valuable source that can be read, analysed and continuously (re)interpreted. In cases where the contextual framework is set properly (Herring 2010, 5–6) and we understand what is going on beyond the written accounts, online texts provide answers to multiple questions that might interest other cancer patients as well as researchers from different fields.

## WHEN DOES LIFE AFTER CANCER START?

As every cancer experience is to some extent unique, cancer narratives concentrate on highly important themes and issues that are personally significant for the respondent. On the other hand, because of the culturally preset rules that guide the process of written self-expression, people select themes and issues for discussions that might also be significant for others, particularly the reader of cancer narratives. This, again, means that the themes that are selected for writing, and are thus often repeated, have a particular significance in the context of cancer experience in the ethnographic sense. Observing cancer patients' online discussions regarding their lives after cancer shows that the question "When does life after cancer begin?" is discussed by participants rather actively. A request to discuss this subject was posted on 19.10.2009 by *Toipilas*, who attends online discussions on a regular basis:

*It is 1½ years since my surgery and there will be regular check-ups for the rest of my life and at the same time I am afraid/hopeful regarding the results of these check-ups. When does "life after cancer" begin? Is it when you stop visiting these pages or are there any better ideas?*

*Toipilas | 19.10.2009 at 22:08:11*

The first answer came one and a half hours later:

*An excellent question, I have been thinking about this, too. In fact, you have to spend the rest of your life with it, no matter how long the life will be. Perhaps they mean the period that ends when the five years of regular check-ups are over and you come out with 'clean sails' on survivors' waters, or at least that's how it should go. Have fun sailing!*

*jaa mullako | 19.10.2009 at 23:53:30*

Some days later a participant called *Cherry* continues in the same vein:

*This is a good question (at the moment it has been a year since falling ill/first examinations) and for my part I can say that perhaps life after cancer starts when it is not in your mind daily...? Perhaps the fear of reoccurrence stays, but the feeling is not so strong as time passes.*

*Before I did not have fears about my future; I found it self-evident that the illness will not return, but now as I continue with work and the check-up is coming closer, the fear has returned to my mind: what if new metastases occur...?*

*Somehow the fear has caused a crisis and my husband finds it difficult to understand...*

*Cherry | 31.10.2009 at 23:54:04*

Another participant, *Esko63*, finds that: “[...] If cancer has once occurred, although removed, it will not leave your mind – the soul will leave first?” (*Esko63* | 1.11.2009, at 17:31:34). *Karlip11*, on the contrary, argues that it is possible to let go of the idea of fearing cancer for the rest of your life if the mind is set on enjoying the day:

*The body recovers sooner. Psychologically it took me three years until I had finally solved all the issues in my head. I decided that was past and gone and I could do nothing about it. It was better to forget. At first I was convinced that I had to leave. While at work, I had seen how cancer killed. In March it is five years since my cancer was discovered and I have received a breast implant; however, for more than three years I was one-breasted. Now I am in the prime of my life. I have other diseases. In the beginning I was at home from work for a year. Then came the retirement decision. I did not have to work even a single day after the diagnosis. In May I am having the final check-up. I live day after day, full of vigour and vitality. All the best to you!*

*karlip11* | 4.11.2009 at 14:01:43

According to the writing analysed here, people experience phases of shock, denial, anger, trade, depression and acceptance repeatedly; meaning that in the inner narrative, accepting the idea of dying must be continually negotiated (Paal 2010, 69–71). Cancer narratives reflecting selected parts of the inner narrative demonstrate that, when being confronted with a fatal illness, it takes time to reach a point where a person accepts that life will not last forever. Furthermore, even if people accept having cancer or being terminally ill, it does not mean that they stop fighting for their lives. Typical of cancer narratives is the understanding that people reach about how to cope. This kind of awareness makes people more tolerant and unwearied.

## BACK TO WORK?

The analysis of written cancer narratives has shown that cancer diagnosis causes people to lose their negotiated identity and their previously established place within society (Paal 2009a, 39–51). Loss of one’s self occurs quickly as people are pushed out of their daily routines. The ability to go to work and carry out one’s daily duties is particularly understood as the symbol of a functioning human being. Therefore, the ability to work should be understood as an important part of personal identity. For many people, particularly in urban areas, the workplace and work colleagues represent the most important social networks. Additionally, work ensures the earnings necessary to manage everyday money matters on a social level. Without the ability to work, people feel isolated. This means that in addition to physical concerns, a serious illness also causes people to be confronted by economic and social problems, which

exclude them even further from 'normal' life (Hayes & Nutman 1981, 14).

After the treatments are over, one of the central issues for cancer patients is the question of returning to work. The illness stories published online demonstrate that having cancer changes the cancer patient's position within social frameworks and therefore returning to work is experienced as a great challenge containing physical and psychological worries:

*Hi there,*

*I found it nice to return to work, although quite soon new treatments began (well, I do not have breast cancer). I tried to go to work between the treatments, but I could not. I managed half a year and then gave up. Of course the return made me nervous, but my boss and work colleagues were really understanding and I did not feel myself at all as 'diseased'. My boss had to reorganise the days when I was treated. Otherwise I worked as always. I am chronic(al)ly ill. Perhaps I can never return to work. It is worth listening to our bodies. We are all individuals with our cancers. Good luck!*

*reetu | 21.10.2008 at 18:09:36*

*Breast removed in January, then cytostatics and X-rays. Now I just take hormones. I have been back to work since August. It was really nice to go back to work, but now everything feels like before. I manage well (my job is not physically challenging), and no one has asked how I feel, so I am supposedly quite normal, although I still wear a wig. Back to work!*

*Vaarain | 24.11.2008 at 17:58:53*

In given examples as well as in other texts posted in this discussion chain the respondents refer to the fact that 'to their surprise' they were handled as 'normal' and not like 'diseased' by their colleagues when they returned to work. Such intertextual interaction taking place between different life-logs brings out the idea of pro-activeness that is hidden in popular thought, mediated as it is by various communicative means including written narratives. It demonstrates how in popular thinking cancer is, despite its slowly changing socio-cultural image, still considered so stigmatising that it directly affects cancer patients' reasoning and influences their sense of self.

The dominant beliefs, myths, and ideologies that underlie the behaviour towards cancer patients on a societal level are: firstly, respect paid to the dying (leaving sufferers alone); secondly, the fear of contagious illnesses; and thirdly, avoiding a potential norm-breaker (Paal 2009b, 51–52). With these culture-bound ideas in mind, it is worth emphasising that despite continuous social control, the path of illness is very personal. For cancer patients this generally means an inner challenge hidden from outsiders. In order to accept and correspondingly also to deny the culturally set 'label', people carefully analyse their past behaviour and individual life course. This inner negotiation process examines the reasons for falling ill, and at the same time

helps the sufferer cope both with the idea of being ill and with the search for possible ways out. According to cancer patients' online accounts, such negotiation processes make inner growth possible. After experiencing exclusion from 'normal' life, people realise that, in fact, they are not able to completely control their lives, which also makes returning to work complicated in some cases.

Moving towards analysing the problems of cancer patients, I emphasise that social and cultural misjudgements towards cancer patients are one of the greatest challenges to all of them and therefore discussing this issue is very important. As people are afraid of a social judgement and the fact that their colleagues would treat them differently or avoid them as 'diseased', there are also physical challenges involved in returning to work:

*Two working days behind :) My hand is swollen like baking dough and last night I had some pain. Luckily lymph-treatments ahead on Friday, then the pain is finished!*

*I had no chance to get used to working slowly as there is a constant lack of staff. The patients are psychologically and physically challenged. Luckily I got some help when I asked.*

*Must admit it was nice to go back to work. Now I feel I belong somewhere again!!*

*I hope that I will manage and and so will my hand... Would be terrible to be back on sick leave, but time will show.*

*toukokuu | 3.3.2009 at 22:04:29*

Two weeks later *toukokuu* writes again to say that she is off from work as her hand did not endure the pressure (*toukokuu1 | 17.3.2010 at 12:32:09*). *Toukokuu's* story is a typical example of a breast cancer patient's daily struggle, which does not only concern returning to work, but also managing daily duties and domestic work.

Unlike people who need to work because they need to feel part of the working society, many patients have to consider the economic sides of staying at home or going to work. If the economic situation of the family or the social support provided by the state or insurance companies was sufficient, there would be no need for half-cured people to go back to work, unless they wish to do so. In most cases people have no choice, and therefore deciding between individual health and family economics may cause much trouble.

In online discussions cancer patients may share their criticism towards the lack of information regarding their rights to stay at home after the treatments are finished, as well as their rights to return to work with limited work hours. They also claim that 'chewing oneself through the walls of bureaucracy' can be tiring and make you feel 'like having a full time job', particularly shortly after physically and mentally exhausting cancer treatments (*Kristitty Lilja | 10.2.2009 at 11:10:28*).

Naturally, as people are very different, we can also find accounts among the online illness stories, in which people admit that the opportunity to stay at home after

Piret Paal: Illness narratives

cancer treatments has been the best thing ever happening to them, as it removed pressures and gave time to take care of themselves. Usually this is the case with elderly people, who have already been active in their working lives for several decades:

*I did not have to work at all after the diagnosis. This was good as my work means taking care of dying cancer patients. I was on sick leave for a year. I had other problems as well. After a year I retired. This was the best solution for me. If you feel that you cannot manage at work, go on sick leave.*

*karlip11 | 24.11.2008 at 16:08:05*

Above all, following the discussion of returning to work after cancer treatments shows that people still need much support to overcome their inner confusion, to manage the physical suffering caused by radical treatments, and to find the best way to continue with their everyday lives. The individual's ability to manage these questions varies, and thus people find themselves in widely differing situations as their "life after cancer" begins. However, the examination of all responses demonstrates that one of the dominant motivations for expressing individual experience seems to be the fact that people want to share their experiences and feelings regarding their illness experience in order to help and support others in similar situations.

#### DISCUSSIONS ABOUT HAVING CHILDREN AFTER CANCER

One topic that is often raised on the cancer patients' discussion board deals with having children during cancer treatments or planning them once the treatments are over. This is a fascinating subject as, firstly, it contradicts the myth that only older people have cancer, and secondly, it well demonstrates cancer patients' hesitations regarding their possibilities of regaining a 'normal' life:

*I was diagnosed with lymphoma in August 2006. I married in June and tried to have a baby with my husband immediately. Thank God I did not become pregnant. Thanks to the new medication we can try having a baby next year if the cancer stays away.*

*Now I am really depressed. The closer we get to August 23, when my cancer was first diagnosed, the more I think of things that took place a year ago. I think of what will happen if I become pregnant next year and the cancer reoccurs and I lose my child? Or what if I never try having a baby and I stay healthy for the rest of my life? Then there will be a big part missing from my life, my own child. Am I selfish because I wish to have a child? What if I fall ill with cancer for example in five years' time and the child has to suffer with me?*

*Has anyone else experienced such feelings?*

*nallu80 | 4.8.2007 at 09:21:12*

The message from *Nallu80* has received 19 responses so far, but like other topics, it is an open discussion board that is continuously accessible for new comments and stories. Similar issues arose earlier and afterwards under new subtitles. The first response to *Nallu80* makes a reference to another Internet site where a similar discussion was going on a little earlier. However, a participant named *Kirsikka* decided to share her experience as a response to *Nallu80*'s post:

*I had a terrible desire to get a second child 4 four years after cancer treatments (spring 2004). Despite everything. I was 24 weeks pregnant when they found out that I had cancer metastases in my bones and the spine was already broken. They assured me that the best thing to do would be to have an abortion and start with new treatments to survive at least a few years. Even if it is in a wheelchair. I understand that this would have been reasonable. However, I refused to have the abortion and told them that I would be the growing ground for life as long as the air goes in and out. I had terrible pains, was completely bedridden, and wore diapers for about two months . It was a nightmare. I did not want to give up my decision, although I had the opportunity. Thanks to the doctors for that! I had a Caesarean in week 32 and the baby was healthy. I continued with treatments when the wound had healed a little. Seven people lifted me into the X-ray machine to avoid the spine moving. As the treatments started to work, I learned to walk again and luckily the spinal cord was not damaged. There was a cure that helped. And here I am. The child grows, is lovely and witty. I go to work and feel good. Well, sometimes the missing vertebra reminds me of itself if I put too much pressure on my back.*

*What is the morale of this story? Act as your HEART tells you. Then you cannot be mistaken, whatever happens...*

*Kirsikka | 6.9.2007 at 16:44:00*

Another woman shares her own, slightly different, story:

*Hi,*

*And good luck to you with the baby, do not be afraid what kind of mother you will be, you will become the best possible mother to your child :)*

*I am in a slightly different situation. I fell ill in August 2007 and I had had a baby, our fifth child, in July. It was a terrible time with fears and depression, I thought that if I did not survive, my children would lose their mother and the smallest will never learn to know me and would not remember me. The fears were terrible... I also thought why I had delivered babies into this world if I was not able to bring them up, and that it would have been so much easier if I had been alone.*

*But as the treatments began and life slowly continued in its normal way, I began to think that luckily, whatever happened, I had those lovely children, five totally perfect people I have given to this world and that was a thing that I would never regret! They are also the*

## Piret Paal: Illness narratives

*ones that give me strength and help me get better and believe in getting well again; I cannot give up!*

*Wishing you courage and if the doctor has given you permission to have children, then give it a try :) As you said yourself, you might be healthy till the end of your life and regret not having a child... Sunny days to everybody.*

*cry | 9.3.2008 at 11:08:41*

The period spent in healthcare institutions is merely outlined by the surgical and other procedures in terms of removing diseased cells and tissues from the patient's body. At the time when the body is treated and attempts are made by the medical personnel to remove cancer cells, people often suffer from lack of spiritual support. This is a phenomenon generally connected with the attempt to solve personal problems alone, although this does not exclude the possibility of a real lack of professional support, for example in cases like infertility caused by surgical or chemical treatments.

It is only natural for people to feel that cancer has ruined their lives; however, the online discussions show that patients who have suffered from cancer in the early stages of their adult lives, similarly to elderly patients search for a new, somewhat more fulfilling life and one possibility for it is having children. The sincere hope to become a parent expressed in cancer patients' online discussions proves that "life after cancer" as a normal person is possible, and that despite the fears, continuous doubts, and pressures put on people by their daily lives, cancer patients believe that every day should be used for living and, if possible, also for perpetuating life.

## REGAINING PERSONAL IDENTITY IN WRITING

In the culturally stigmatised cancer patient's role, people are forced into a situation in which personal identity becomes loose in various ways. The cultural stigma of cancer puts cancer patients under psychological pressure. Biomedical treatments add physical suffering, while at the same time leaving patients alone with their individual concerns. This kind of experience of losing control of one's own life is understandably the one that can never be forgotten and thus the struggle to regain control over one's life can be defined as one of the central issues in cancer patients' online life-logs.

During the writing process certain tendencies are used to expose the intended goals, such as the influence and meaning of illness and regarding the individual's life-course. In terms of understanding authorial intentions, the author's evaluation of the whole illness process gains a significant position. Authorial evaluation contains the comparison of the periods before and after the diagnosis, and also examines inner sensations in different temporally and spatially defined situations. Although it may seem like an individual negotiation process, it holds a communicative value, which

makes the descriptions of individual experiences particularly interesting. This means that the online discussions regarding life after cancer draw, above all, upon 'responsive' understanding, meaning that a composed text has its goals in terms of reception. The dialogic imagination characteristic of illness narratives is particularly significant as different authorial intentions convey the individual, socio-cultural, and societal expectations of the subject.

Contrary to cultural expectations, cancer patients' online discussions prove that a painful death does not necessarily result from the cancer experience. As many cancer patients do in their writings, I want to point out that 'the end' (although it is difficult to define it accurately) of the cancer experience actually marks the beginning of a somewhat different life. Patients who have survived cancer analyse their lives before falling ill; they recall their past behaviour and reasoning and hope to make a new start. Anne Hunsaker Hawkins has noted that the myth of rebirth is central in many pathographies (Hawkins 1999, 33). This particular myth is an important organising construct that concentrates on the traumatic experience and personal change. In many pathographies, as well as illness stories published online, life after cancer is interpreted as a new opportunity. People experience things that they have only considered before, change attitudes and manners, think more about their own wellbeing. Linda M. Hunt, who has analysed the illness stories of Mexican cancer patients, has produced similar results. She has noted by the same token that in the course of rebuilding a workable image of themselves, the world, and their place in it, patients generate narratives that forge an identity around patient-hood in ways that negotiate issues of social empowerment (Hunt 2000, 92; see also Paal 2009b, 55–56). The ideas presented in cancer patients' online discussions support Hunt's statement, revealing that, despite its devastating impact, cancer changes patients' lives for more positive in many ways by opening new (unexpected) perspectives. Naturally, coming to such conclusions needs time and suitable conditions and even if people cope with the idea of having cancer, they will always carry this experience in their minds.

From the reader's point of view, our understanding of what the cancer patients want to express in their written texts relies on our socio-cultural comprehension processes concerning this particular illness. The schematic structure of cancer-related events has a particular function in bringing together the respondents and their audience. The evocative times, such as the time after cancer treatments, connected to certain milieux may be interpreted as the writer's attempts to mediate the opinions, ideas and feelings that cancer patients experience at various communicative levels. Furthermore, the 'dialogic imagination' characteristic of cancer patients' online accounts allows the expression of the author's experiences and ideas not only at a communicative level, but also – by conveying thoughts that have never been externalised before – at the level of thoughts and feelings.

## CONCLUSIONS

Like any set of self-expression texts based on personal experience and cognition, these Internet accounts are multilayered. The most significant differences here derive from the individual illness course underlined by the unique nature of cancer, which after the treatments are finished leads to “life after cancer”. Examining this period in cancer patients’ lives allows a description of the changed life situation and the patients’ attempts to participate in everyday life like they had before. Some of them are more successful than others, although all of them have learned a lesson that has left its imprints on their life histories.

Above all, based on cancer patients’ online publications, life after cancer represents a period when cancer patients have to understand and accept the single dimension that belongs to the process of having cancer – life is a continuous confrontation and response to the fact that we will all die. Accepting this fact is often interpreted by cancer patients as a valuable lesson on life, which helps to continue with living and overcome the challenges provided by psyche and soma as well as daily living, work and family life.

For many people their online relationships with other participants work as powerful wells of spiritual help; however, it is not enough to soothe patients’ worries about their life expectancy or their secret wishes of becoming a parent in the future. This means that health professionals who take care of cancer patients should also be aware that the situation has changed to a certain extent; because of early detection techniques many people are diagnosed with cancer earlier in life, but after the treatments they wish to continue with their lives as normally as possible. To make this feasible, when dealing with patients’ questions of fertility, possibilities of having children or attending work after cancer treatments should also be discussed in detail, so as not to cause unwanted harm to those already suffering.

## NOTES

- 1 Finnish Cancer Registry, On-line forum, <http://www.cancer.fi/keskustelut/>.
- 2 Paul Ricoeur has stated that composing a life story is a meditation between Man and the world (referentiality), between Man and Man (communicability) and between Man and oneself (self-understanding) (Ricoeur 1991, 20–33).
- 3 José van Dijck uses the term ‘lifelog’ to refer to the kind of personal weblog that is a mixed form of handwritten diaries of the past and a new understanding of sharing personal information (van Dijck 2004).
- 4 One possible method of web content analysis is the Computer-Mediated Discourse Analysis or CMDA. The basic methodology of the CMDA is described by Susan Herring as language-focused content analysis supplemented by a toolkit of discourse analysis methods adapted from the study of spoken conversa-

- tion and written text analysis (Herring 2004, 338–376).
- 5 See more: Finnish Cancer Registry, Activities, <http://www.cancer.fi/en/activities/>.
  - 6 (1) Patients taking life-supporting medication, (2) treatments and follow-ups, (3) my child has cancer, (4) cancer patient in the family, (5) male cancers, (6) female cancers, (7) young cancer patients, (8) do I have cancer, (9) palliative care, (10) mourning group, (11) cancer and worldview, (12) quitting smoking, (13) general information about cancer, and (14) life after cancer.
  - 7 This is why I did not ask for permission from the original authors to use the published texts in this article . Making a personal contact with participants would have revealed too much about their true identities, which certainly would have affected the value of used texts as plain tools of social control mediating the meanings interesting from the cultural perspective.
  - 8 Some experts of online publishing share the opinion that the first rule of online publishing is that there are no rules (AOP 2010). However, cancer patients' online accounts, like the majority of online content, are strictly written.

## RESEARCH MATERIALS

Finnish Cancer Registry, On-line forum, [http://www.cancer.fi/keskustelut/keskustelufoorumi/elama\\_syovan\\_jalkeen/](http://www.cancer.fi/keskustelut/keskustelufoorumi/elama_syovan_jalkeen/) [10.07.2010]

## REFERENCES

- AOP 2010 = Association of Online Publishers 2010: The first rule of online revenue: there are no rules 25.2.2010, <http://www.ukaop.org.uk/news/newrulesofrevenueeventreport1948.html> [10.11.2010]
- BAKHITIN, MIKHAIL 1981: *The Dialogic Imagination. Four Essays* – Caryl Emerson & Michael Holquist (trans.). Austin: University of Texas Press.
- FRANK, ARTHUR 1995: *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: Chicago University Press.
- GARRO, LINDA C. & MATTINGLY, CHERYL 2000: Narrative Turns. – Cheryl Mattingly & Linda C. Garro (eds.), *Narrative and the Cultural Construction of Illness and Healing*. Berkeley-Los Angeles-London: University of California Press.
- HAWKINS, ANNE HUNSAKER 1999: *Reconstructing Illness. Studies in Pathography*. West Lafayette, Indiana: Purdue University Press.
- HAYES, JOHN & NUTMAN, PETER 1981: *Understanding the Unemployed: The Psychological Effects of Unemployment*. London & New York: Cambridge University Press.
- HERRING, SUSAN 2004: Computer-mediated discourse analysis: An approach to researching online behavior. – Sasha A. Barab, Rob Kling, & James H. Gray (eds.), *Designing for virtual communities in the service of learning*. New York:

- Oxford University Press.
- HERRING, SUSAN & SCHEIDT, S. C. & BONUS, L. A. & WRIGHT, E. 2005: Weblogs as Bridging Genre. – *Information, Technology & People* 18(2).
- HERRING, SUSAN 2010: Web Content Analysis: Expanding the Paradigm. – J. Hunsinger, M. Allen, & L. Klastrup (eds.), *The International Handbook of Internet Research*. Berlin: Springer Verlag.
- HUNT, LINDA M. 2000: Strategic Suffering: Illness Narratives as Social Empowerment among Mexican Cancer Patients. – Cheryl Mattingly & Linda C. Garro (eds.) *Narrative and the Cultural Construction of Illness and Healing*. Berkeley-Los Angeles-London: University of California Press.
- JAHN, MANFRED 2000: Stanley Fish and the Constructivist Basis of Postclassical Narratology. – Bernhard & Rieuwerts, Sigrid (eds.) *Anglistentag 1999 Mainz: Proceedings*. Trier: WVT.
- KÕIVA, MARE 2010. Patsiendinarratiivid internetis. – Paal, Piret (ed.) Inimene, tervis ja haigused. Terviseteeemaline artiklikogumik “Medica”. Tänapäeva folkloorist 9. Tartu: EKM Teaduskirjastus, 217–250.
- KÕIVA, MARE 2009. Online Medicine. Communication and Narratives. – Kõiva, Mare (toim). Media & Folklore. Contemporary Folklore IV. Tartu: ELM Scholarly Press, 162–183.
- LABOV, WILLIAM 2004: Ordinary events. – Fought, C. (ed.) *Sociolinguistic Variation: Critical Reflections*. Oxford: Oxford University Press.
- LEHMANN, ALBRECHT 2007: *Reden über Erfahrung. Kulturwissenschaftliche Bewusstseinsanalyse des Erzählens*. Berlin: Reimer.
- PAAL, PIRET 2009a: Cancer and Emotions – The Moment of Diagnosis and Metaphoric Transformation. – Tove Ingebjorg Fjell (ed.) *Tidsskrift for kulturforskning Vol. 8 (4) 2009*.
- PAAL, PIRET 2009b: Sairauden merkityksestä syöpäpotilaiden kirjoitetuissa kertomuksissa. – Jouni Kumpulainen (ed.) *Lähde. Historiallinen aikakauskirja 2009*.
- PAAL, PIRET 2010: *Written Cancer Narratives. An Ethnomedical Study of Cancer Patients' Thoughts, Emotions and Experiences*. Tartu/ Helsinki: ELM Scholarly Press.
- RICOEUR, PAUL 1991: Life in Quest of Narrative. – David Carr (ed.) *On Paul Ricoeur: Narrative and interpretation*. London & New York: Routledge.
- VAN DIJCK, JOSÉ 2004 [online]: Composing the Self: Of Diaries and Lifelogs. – *Fibreculture Journal, issue 3*, [http://journal.fi/breculture.org/issue3/issue3\\_vandijck.html](http://journal.fi/breculture.org/issue3/issue3_vandijck.html) [09.07.2010].

**Piret Paal (b. 1977) is a folklorist interested in narration and illness interpretations of various forms. She has studied folklore at the Universities of Tartu, Turku and Helsinki. Currently she is a researcher at the Department of Spiritual Care, Ludwig-Maximilian University of Munich (Germany).**