

5. Popular Images of Cancer in Modern Discourse

The culturally defined meaning of cancer, that of a serious illness, the expectations of patient illness behaviour and their processes of adopting the role of patient are central themes in the cancer patients' narratives analysed in this work. The heterogenic nature of cancer narratives makes it possible to understand why there is a great difference in individuals' interpretations concerning the various culturally accepted expectations connected with cancer. The differences are understandable because of the variations in personal cancer experience and the individual's life course in general. Despite these differences, the available interpretations often tackle similar themes and topics to those that appear as characteristic to the culturally framed discourse on cancer.

In this chapter I shall discuss how cancer is patterned and interpreted within wider society, as illustrated by the cancer narratives. To understand the meaning of cancer in popular discourse I use the concept of explanatory models, suggested by Arthur Kleinman in his study on patients and healers within the context of culture (1980). In his work, Kleinman deals with illness narratives from different cultures and says that explanatory models are responses to particular situations and are therefore idiosyncratic, changeable and heavily influenced by both personality and cultural factors (Kleinman 1980, 104–118). As a result, explanatory models, when applied to illness, consist of notions about an episode of illness and its treatment as employed by all those engaged in the illness process. According to Kleinman, explanatory models are partly conscious and partly subconscious, and are charac-

terised by vagueness, a multiplicity of meanings, frequent changes and the lack of sharp boundaries between ideas and experience. The basic idea of explanatory models in healthcare is to guide a person through a particular illness process or pathological drama by finding the correct cause of the condition and negotiating the appropriate treatments.

In this thesis I am interested in how people explain cancer as a culturally meaningful illnesses from a personal point of view. Here again, I wish to reiterate that popular reasoning is framed by the linguistic ideologies that mediate culture-bound ideas. Thus, the construction of a particular discourse is based on individual, and also cultural, factors. This means that when people are diagnosed with cancer, an internal dialogue occurs between their culturally agreed understanding of cancer, and its meaning to that person. Such reasoning is constantly modified, being specified and re-interpreted based on individual experience. In this way people create their personal explanatory models, which, although unique, provide five main aspects to illness (Helman 1981, 549):

- The aetiology or cause of the condition (Why has it happened? Why has it happened to me?)
- The timing and mode of the onset of symptoms (Why now?)
- The pathophysiological process involved (What has happened?)
- The natural history and severity of the illness (What would happen to me if nothing were done about it? What are its likely effects on other people?)
- The appropriate treatments for the conditions. (What should I do about it?)

Despite the vagueness and different interpretations occurring in the materials under the study, I argue that the explanatory models relating to cancer form a set of tradition-based beliefs comparable to the ethnomedical records explored in the previous chapter. Like any other set of popular beliefs, respondents' ideas on cancer are heterogeneous and contradictory. Guided by language, people perceive these culture-bound ideas during the socialisation process and thus a particular cultural context takes on its characteristic features. Features that are then compared with individual experiences. As human understanding is open to continuous interpretation, individual interpretations are likely to correct themselves through contact with surrounding culture and

in this way a certain stability is maintained. In this manner certain discourses and their characteristic features are defined.

Within the literary sub-group that is pathographies, this culture-bound inner negotiation becomes fixed on paper. Firstly, people reconstruct their illness experience: they point out their individual coping methods, describe the illness process and relate their private attempts to understand the significance of cancer in their lives. Thus, secondly, the result is that tradition-based folk beliefs become contextualised, and are therefore more open to interpretation than the ethnomedical records examined in the previous chapter. Thirdly, when analysing these beliefs or explanatory models, it is important to remember that these discussions, fixed in writing, represent at the same time the writer's inner reasoning and culture-bound ideas, as well as being their response to a questionnaire destined for the archives. These three aspects form the basis for the 'dialogic imagination' characteristic to ethnographic writing.

The Problematic Concept of Cancer

Today the concept of cancer often causes people some controversial feelings. Many writers admit they despise the sound of the word. Therefore, when participants write about the process of their illness, they avoid the use of the word cancer. Doing so may be interpreted in this context as an ideology reflecting culturally developed ideas relating to cancer. This ideology restricts word use and sets boundaries on individual self-expression. It is very common for the term 'cancer' to appear in cancer patients' narratives deictically. Which is to say that instead of using the noun 'cancer', people refer to their illness using the pronoun *se* (it) or *tämä* (that). Respondents use various euphemisms, which, in their minds, describe the aggressive nature of cancer: "*Vielä tänäkin päivänä yritän kaiken mahdollisin keinoin välttää joutumasta käyttää sanaa 'syöpä'. Siihen liittyy niin paljon kipeitä tunteita. Sen sijaan yritän löytää aina jonkun lieventävän ilmaisan, kuten 'sairaus'.*" "Until today I try avoiding the word 'cancer'. It has such a strong connotation with feelings that hurt badly. Instead I try to find some more appropriate word, like 'illness'." (418). In the cancer narratives, cancer is called a *piru* (devil) (144), *spitaali* (leprosy) (414, 646), *paha* (evil) (070), *rutto*, *ruttotauti* (plague disease) (033, 136), *käärme* (snake) (095), *susi* (wolf) (383), *vieras* (stranger) (126), and *kuolema* (death) (012,

025, 058, 223, 560, 566, etc.). In order to avoid naming cancer people write about their body having lumps and bumps (*nystyrä, rupi, mökky, pahkura, mätäpaise*). Some of these names will already be familiar from the ethnomedical data described in the previous chapter. Calling illnesses by ethnonyms like devil, evil, wolf or snake was equally common in Finnish folklore.

Several metaphoric expressions are also used to mediate the malevolent nature of cancer. People imagine cancer as something that *syö* (eats), *nakertaa* (bites), or *mädättää* (rots) the body: “It eats me, bites, and rots me” (627). It “enters”, or “conquers”, the human body without the owner’s permission and rapidly changes their life. One participant wrote:

Sana syöpä on niin ikävä, että itse haluan käyttää sanaa pahanlaatuisen kasvain. Syöpä on kuin “syöpäläinen” rotta, jyrsijä, jotakin kauheaa mikä jyrjii ihmisen loppuun ilman toivoa. Sana pitäisi muuttaa pehmeämmäksi. Itse sairaudesta on tarpeeksi.

The word cancer is so awful that I prefer the words bad natured growth. Cancer is like a ‘parasite’ rat, gnawer, something awful that gnaws the person entirely without any hope. They should change the word to be milder. The illness is [hard] enough. (612)

Mikä on syöpä? Syökö se jotenkin ihmistä ja kuinka? Onko se jonkinlainen mato, joka nakertaa pala palalta? Rakas mummu, se mato syö mummun. Rankaiseeko jumala minua, kun olen ollut tottelematon ja laiskakin, haaveillut kaikenlaista ja ajatellut vain itseäni.

What is cancer? Does it eat people, and how? Is it some kind of worm that eats piece after piece? Dear granny, this worm eats my granny. Does God punish me because I have been naughty and lazy, dreaming about everything and thinking only about myself? (434)

Sana syöpä on kauhea asia kun se kerrotaan. Kaikki eletty elämä tulee kuin yhdessä hetkessä silmien eteen. Siinä miettii, miksi on elänyt, miksi on tehnyt niin kovasti työtä, kun pitää näin kärsiä.

The word cancer is such an awful thing as it is told. All lived life comes like in one moment in front of your eyes. There you think, why have you lived, why have you worked so hard if you have to suffer so much. (163)

Images of illness as some sort of malicious outsider are considered typical to primitive cultures. Cancer narratives composed by Finns in 1994 allow the suggestion that people continue thinking in such a manner today. First and foremost it indicates that people respect the power of words, and that they subconsciously sense that by naming

the illness it might gain power over them. In the context of cancer narratives, avoiding the word cancer may be interpreted as an ideology reflecting the culturally developed ideas relating to cancer. This ideology restricts the word's use and sets boundaries on individual self-expression in modern cancer discourse. However, as is typical to folk belief, this idea also works the other way around: by giving illness a name and shape we gain control over it.

In cancer patients' minds the concept of cancer lacks certain qualities required for it to be explained rationally. One leukaemia patient even demanded: "*Sairaudella täytyy olla nimi, mutt  my s olemus tai muoto*", "an illness needs to have a name, but also a shape or form" (506). Thus, we may suggest that without giving illness a proper name and shape it is difficult to unite the illness with personal explanatory models. Personification, or at least naming an illness, makes it acceptable for patients and helps the coping process to continue. This kind of reasoning is independent of scientific cancer discourse.

The scientific explanations relating to cancer also demonstrate that, from the biological point of view, carcinomas are particularly challenging to define. The British evolutionist Mel Greaves has pointed out a significant aspect of cancer, namely that, "the illness we call cancer has extraordinarily diverse features including its causation, underlying pathology, clinical symptoms, therapeutic response, and outcome or chance of cure. In a sense, every patient's cancer is unique, which is part of the difficulty" (Greaves 2001, 3). This means that cancer represents a collection of numerous disorders of cell and tissue function and that the only special biological property in common is the territorial expansion of a mutant clone. For medical doctors this means that they are able to make various suggestions regarding the possible illness origin, but these suggestions according to the current state of cancer studies have something like 80% certainty. It also means that because of cancer's unique nature, every time it occurs, it is challenging to recognise the symptoms, suggest appropriate prevention methods or decide on suitable treatments, or to make a prognosis regarding the outcome. As I shall demonstrate below, for cancer patients this means that their primary question: *why me and why now?* is often left without an answer, and it also means that in reality people cannot compare their individual illness process with other seemingly similar cancer cases. As doctors are unable to give rewarding answers, either because of the lack of biological evidence or adequate communicative

(read: healing) skills, patients negotiate their lives and living conditions and come up with popular explanatory models, including their own interpretations of cancer's name and shape, and also its origin and possible cures. As cancer narratives indicate, such interpretations are typically based on personal life and lived experience.

Before moving further, I wish to emphasise that because of this ongoing unawareness of cancer, the concept of cancer has gained two meanings in everyday communication: rational and irrational. Rational meaning relates to the numerous cell and tissue dysfunctions that take place in the human body, and in this context the human body is interpreted as a dysfunctional physical object that must be mended. This approach is common among medical professionals and scientists, although from the cultural point of view other people also share this reaction. For patients, cancer's rational meaning is mainly connected with bodily experience, such as tests during follow-ups, surgery, chemical treatments, and the period of recovery. On the other hand, among ordinary people cancer also has an irrational meaning connected on an emotional level to human suffering, pain, and death. It may be described as a 'sense experience' deriving from socio-historical context. Approaching cancer as a sense experience allows an explanation of why, in popular discourse, cancer is often recognised as an 'evil being' with supernatural qualities.

When analysing popular discourse it is not possible to make a clear distinction between the rational and irrational meanings of cancer because during the communication process people employ both meanings at the same time (Quine 2008, 64–65). This indicates that the rational and irrational meanings have to be interpreted as incoherent and overlapping concepts; and where differentiation is required, the speech situation proposes which meaning is to be used.

Common problems associated with recognising cancer

The previous diachronic insight into Finnish folk medicine revealed that compared to other illnesses, cancer had a secondary relevance in the past (see Chapter 3). The rapid growth of cancer occurrences among the Finnish population has changed the position of cancer among other illness, so that during the second half of the 20th century it became one

of the most significant illnesses. This increase in instances of cancer (Koskenvuo 1994, 43) has also affected people's attitudes towards the illness. In contrast to previous times, cancer is no longer considered an illness that only affects old people:

Lapsuudessani pelkäsin, kuten sen ajan lapset yleisesti, pimeään ja kummitusten ohella tulirokkoa ja lapsihalvausta, isona poikana jo keuhkotautiakin ja kovasti. Pakollisia tuhka- ja vesirokkoja ei pelätty. Kurkkumätä ei myöskään kuulunut tavanomaisten pelkojen joukkoon ja kun vain vanhoilla ihmisillä saattoi olla kasvi, sitä ei ollut syytä pelätä. [---] Sodan jälkeen ei keuhkotauti enää ollut kovin yleinen. En pelännyt sitä ja olin varma, etten sairastu siihen. Sydänvika oli myös unohtunut. Mutta oli tullut uusia tauteja, kuten syöpä. Syövästä alettiin puhua yleisesti. Entisestä vanhojen ihmisten taudista, kasvista, oli tullut syöpä, syöpäkasvain.

In my childhood, as was common to children of that time, I was afraid of darkness and ghosts, but also scarlet fever and polio, and as I grew older I was also very afraid of tuberculosis. Measles and chicken pox were seen as compulsory, but they were not something to be afraid of. Diphtheria did not belong among the usual fears and as only old people had growths there was no need to be afraid of this. [---] After the war tuberculosis was not so common. I was not afraid of it and I was sure I would not get it. I also forgot about heart failure. But new illnesses had appeared, like cancer. People began to talk about it. The old people's disease, 'growth', had become cancer, carcinogenic growth. (650)

In her book *Laientheorien zum Krankheitsbild "Krebs"* (Lay Theories about the Image of Cancer, 1989) German folklorist Gudrun Schwibbe points out several interesting problems that people face when they deal with cancer. Schwibbe's study demonstrates that although the popular beliefs concerning the illness origin, symptoms, prevention, treatments and prognosis are close to scientific statements about cancer, people are in many ways confused by these explanations and have a constant need for more accurate information (Schwibbe 1989, 161–162). For example, the most common symptoms of the early phases of cancer are tiredness, loss of appetite and weight, paleness, and in some cases also continuous fever or pain. The main problem is that many of these symptoms can also be psychosomatic, and if these symptoms appear at times of external tension, such as work pressures or partnership problems, people hesitate for a long time before they seek medical advice, which then reduces the chances of recovery.

The fact that the cause(s) of cancer is/are still not entirely clear raises aspects for discussion. According to cancer narratives people have problems connecting pain with cancer. This is illustrated in, for example, official descriptions of breast cancer symptoms, which state that pain in the breast should, at least typically, not be considered a sign of cancer (*Rintasyöpä*). Individual experience (and belief), however, is the opposite:

Kun nyt kelaan tapaukseni kulkua mielessäni, muistan kun eilistä päivää kesää 1976, jolloin rupesin tuntemaan outoa kipua vasemman rinnan kohdalla. Syöpä ei edes käynyt ajatuksissani, koska se vähä, minkä rintasyövästä tiesin oli, että se ei ainakaan anna kipuoireita. Näin ollen oletin syyksi jotain muuta, esim. ylirasitus puutarhatöissä tms.

As I now rewind the events in my mind I remember the summer of 1976 as it were yesterday; then, I first began to feel pain in my left breast. The possibility of having cancer never entered my mind as the few facts that I knew about cancer said that cancer never caused a feeling of pain. So I considered other reasons, for example doing too much in the garden or something like that. (147)

On the other hand, the valuable information that cancer organisations share has makes people aware that lumps or bumps suddenly appearing in the body could possibly have carcinogenic origins. For the same reason blood or other suspicious liquids in excrement or urine, and also connected with breasts or birth marks, are also taken very seriously and interpreted as *pahan merkki*, or the “sign of evil” (070).

According to cancer narratives trained doctors also have problems recognising cancer. As a matter of fact, in numerous narratives people describe their efforts to be taken seriously by professionals working in the healthcare system. As they point out, some doctors also make their primary decisions based on popular beliefs:

Ensimmäiset lääkärin sanat olivat: “Ette ole ollenkaan sellainen ihminen, joka voisi sairastua syöpään”. Olinko minä jokin erikoistapaus? Minulla oli silloin korkea kolesteroliarvo, peräti 17. Oliko se syy? Silloin lääkärit olivat vielä yli-ihmisiä, enkä minä uskaltanut avata suutani kysykseni mitä lääkäri tarkoitti.

The first words that doctor told me were: “You are not at all this kind of person who could fall ill with cancer:” Was I some kind of special case? At that time my cholesterol level was 17. Was that the reason? At that time doctors were superhuman and I was afraid to open my mouth to ask what he meant. (030)

Tilaan lääkärin ja lääkärissä olen jo tammikuussa. Lääkäri vähättelee asiaa ja sanoo, että syöpä on kovin harvinainen rinnassa näin nuorella. Odotellaan, kyllä se siitä häipyy. Mutta eipä tämä kaveri häivy. Itsepintaisesti se vaan siinä jököttää. Helmikuussa olen lääkärissä jälleen, mutta lääkäri ei anna lähetettä vielääkään jatkotutkimuksiin. Rauhoittelee vain.

I make an appointment and visited the doctor in January. The doctor underestimates my concerns and says that breast cancer is very uncommon among such young people. Let us wait and it will disappear. But this fellow does not disappear anywhere. It stays there persistently. In February I make another appointment, but the doctor still does not give a recommendation for further investigation. Calms me only. (048)

Kesällä tuli iso 7-8 cm kyhmy vasempaan rintaan. Kaksi eri lääkäriä sanoi vieläkin, ettei syöpä voi olla noin suuri ja kipeä.

In summer came a big 7-8 cm bump into my left breast. Two different doctors still said that cancer cannot be so big and painful. (271)

Gynekologi tutki rintani ja totesi, ettei siinä ole mitään vakavaa. Hyväs-tellessämme hän sanoi: "Muistakaa rouvua, syöpä ei koskaan arista!"

The gynaecologist examined my breast and as I left she told me: "And remember madam cancer never hurts." (044)

The criticism towards doctors' perceived incompetence is somewhat characteristic to cancer narratives. It appears that people are only given limited opportunity to discuss their health condition and treatments and to give feedback during the pathological drama. Of course there are numerous reasons why people do not share their suspicions directly with people, doctors included, who possibly underestimate their reasoning ability or act in other ways disrespectfully. However, it is understandable that people who are concerned about their health, also feel miserable and are afraid – or do not have the energy – to be assertive or criticise. Therefore, the writing competition was an excellent possibility to share these ideas about doctors' behaviour and decision making during the illness process (see also chapter 7). The critical descriptions available in cancer narratives indicate that sometimes patients must be highly motivated and stubborn when demanding further procedures:

Terveyskeskuksessa jouduin nuoren, penseän lääkärin puhutteluun. Vahingossa, ehkä pelkkää väsymystäni tulin maininneeksi hänelle syöpäpäilyistäni. Hän suorastaan kimmastui:

*"Jaha, diagnoosikin on valmis, kannattikos tänne enää tullakaan?"
Selitin varsin rauhallisesti, että tarvitsen lähetteen N:lle.*

Hän keskeytti ja tokaisi: "Meiltä menee gynekologiset potilaat K:lle, edellyttäen, että aiheutta on. Mutta en minä usko, että teillä mitään syöpää on. Johan sitä tuossa iässä sienimetsässä voi vuotaa tulla ilman syöpääkin." Ääni ja eleet olivat uskottoman ylimieliset.

Koetin rauhallisesti selittää koko sairaushistoriikin jo alkukesästä alkaneesta vuodosta. En ollut käynyt lähelläkään metsää silloin.

"Onko se vuoto kovempaa kuin teidän normaalit kuukausivuotonne, vai vähäisempää?"

"Kuukautisvuoto: Hyvänen aika olen melkein seitsemänkymmenen. Missä tuo miekkonen oikein elelee, kun luulee minulla vielä olevan kuukautiset. Olihan heti alkuun kertonut saavani vain estrogeenia, eikä se ylläpidä jatkuvia kuukautisia."

"Ai eikös teillä olekaan kuukautisia? Minkä takia?"

In the healthcare centre I met a reluctant young doctor. By accident, perhaps because of my tiredness, I mentioned my doubts about having cancer. He almost lost his temper:

"Oh, you have already diagnosed yourself, any reason of coming here at all?" I explained quite patiently that I needed a recommendation to N. hospital.

He interrupted me and said: "Our gynaecological patients all go to S. hospital, in case there is a need for that. But I do not believe that you have cancer. At your age one may have bleeding while picking mushrooms in the forest just like that without any cancer." His voice and gestures were totally arrogant.

I patiently explained my illness course and about the bleeding that started early in the summer. I had not been anywhere near the forest at that time.

"Is this bleeding harder than your normal menstrual-bleeding, or less hard?"

"Menstrual bleeding: for God's sake I am almost seventy. Where is this guy living that he thinks that I still have menstruation. I had said in the beginning that I take estrogens and it does not keep the menstruation ongoing forever.

"Oh, you do not have menstruation? How come?" (024)

I have selected this example as one of the most striking among the analysed materials describing doctor-patient negotiation about the possibility of having cancer. If it did not represent the daily struggle of cancer patients, the story, in which an almost 70-years-old woman is rebuked and then misunderstood for not having a regular menstrual flow, might even be interpreted as amusing, in a disastrous way.

People have problems recognising and accepting cancer because of its vague or sometimes almost nonexistent symptoms and physical consequences. This also means that if cancer is diagnosed during the officially supported follow-ups, and removed during surgery without further complications, it is difficult for patients to admit to being ill and then being well again:

Se onkin tällaisessa sairaudessa vaikeaa, kun todetaan sairaaksi, eikä kuitenkaan tunne itse eikä näy ulkopuolelle, jotta on sairas, sekä hoitojen jälkeen sanotaan, jotta nyt olet terve. Miten voi muuttua sen mukaan sairaasta terveeksi, kun ei ole tuntenut itseään fyysisesti sairaaksi kuin leikkausten jälkeen. Sama asia on vaikea myös perheelle, kun on sairaslomalla ja kuitenkin voi suorittaa kaikki kotityöt. Sääli on kuitenkin pahinta, silloin tuntee sairastavansa sairautta johon liittyy paljon mystiikkaa, kuin olisi leimattu.

The worst thing about this illness is that they tell you that you are ill, although you do not feel ill and it is not visible from outside, and then after treatments they say you are well now. How can you change accordingly, from ill to healthy, if the only time when you have felt ill was after the surgery? It is difficult for the family as well – you have illness leave, but you can't do the housework. The worst things about it is the pity, then you get the feeling that you have an illness that holds within lots of mystery and you feel labelled. (130)

This example represents the change in 'typical' illness course characteristic to cancer, which is foremost caused by medical developments. Because of increased cancer awareness, state supported follow-ups, and highly sensitive diagnostic techniques, carcinogenic illnesses are discovered before people themselves even notice that they are ill. In cases where treatments are successful, it may happen that the process of acceptance or denial of the culturally set stigma, usually described as the feeling of 'being labelled', is more important than the bodily experience and physical suffering connected with cancer. Feeling labelled by cancer is a dominant sensation among cancer patients and therefore I shall return to this question in the final part of this chapter. Before that, however, I would like to introduce modern cancer aetiology among Finnish cancer patients in comparison to folk medical materials.

Popular cancer aetiology

In a similar way to the ethnomedical records, the cancer narratives analysed in this work contain various theories about the reasons for falling ill with cancer. The studied materials indicate that as long as cancer concerns 'other people', and not 'us' or 'me', the rational explanation is fine, but when cancer becomes an individual problem it immediately becomes interpreted as a particular illness with a particular significance in personal life-course. Cancer patients' narratives indicate that this meaningful illness needs an explanation that encompasses the person and his or her personal history, as well as the external and internal factors responsible for cancer. Although today people have lost their contact with the mythological worldview, the underlying idea about illness as some kind of independent being, approaching people from outside, is captured in language and in basic models of thinking. Accordingly, cancer is imagined entering the human body in order to destroy it, whereas the human task would be to understand its origin in order to implement a cure:

Minulle tuli vieras. Se ei ilmoittanut etukäteen tulostaan. Kun se tuli, se asettui hiljalleen taloksi, valitsemaansa paikkaan. Se ei häirinnyt olemassaolollaan pitkään aikaan, vasta myöhemmin sen läsnäolon vaistosi. Silloin se alkoi tarvita minun apuani ja energiaani varmistakseen olotilansa ja siitä seuranneen kasvamisensa. Tajusin, ettei tämä vieras ollut minulle tarpeellinen, eikä sen olemassaololla ollut hyvä tarkoitus. Siksi sen paikka ei olisi luonani, emme siis koskaan voisi asua yhdessä. En ollut kutsunut sitä vieraakseni, joten minulla oli valtuudet järjestää se pois luotani....

I received a guest. It did not let me know about its coming beforehand. As it came, it settled quietly to stay forever. It did not bother me, until later I sensed its existence. It needed my help and energy to be safe and continue growing. I understood that this guest was not welcome and it had no good plans for me. Therefore, its place would not be by me and we could never live together. I had not invited it, so I had the right to get rid of it. (126)

This example describes, in a figurative manner, the nature of cancer as a secretive illness that enters the human body without asking permission or giving any signs of its existence. At some point, however, something internal or external connected with the individual's life *laukaisevat*, 'triggers', the illness and cancer gains control, not only over the body but also over life itself. According to popular thinking,

in order to free oneself from this intruder it is necessary to find the primary reason for falling ill. This may be done only by observing the self, with its inner qualities and individual action, in everyday life. Because of culturally shared knowledge, people have various reasons in mind for what might have 'set off' their illness. Here again it is not possible to give any accurate classification of the popular explanations, as individual attitudes towards these explanations are extremely controversial. Some respondents disagree with the generally accepted aetiologies and thus their narratives may be seen as attempts to prove that the usual explanations are untrue, at least in their own case. Others again adopt existent aetiologies, even if these seem totally irrelevant.

To characterise the popular thinking about cancer aetiology expressed in the analysed cancer narratives, I have adopted the categories suggested in Gudrun Schwibbe's work based on German cancer patients' health beliefs. In her study, Schwibbe divided popular explanations for the origin of cancer into six categories (Schwibbe 1989, 51–52), as follows:

- (1) *unclear*,
- (2) *natural/external*,
- (3) *natural/internal*,
- (4) *psychological/external*,
- (5) *psychological/internal*,
- (6) *behaviouristic*.

Applying Schwibbe's categorisation is problematic because any classification is based on a researcher's subjective expertise. Therefore I shall explain briefly how I have differentiated the materials into the given categories. Firstly, the difference between the external and internal natural reasons is made based on the possibility of individual decision making. For example, people cannot protect themselves from pollution, legally used chemicals, catastrophes or genetic predisposition, although they are able to make decisions on food intake, smoking or using particular drugs. Secondly, the categories describing psychological impact are divided based on similar reasoning; the external aspects are based on social tensions while the internal aspects derive from inner problems. The final category contains reasons that are dependent on individual behaviour and action. Here, the external reasons contain ideas of illness as punishment for individual behaviour, or connect cancer more generally with modern life and lifestyle. The internal reasons, on the other hand, represent certain inner qualities,

which, according to popular reasoning, represent a particularly good trigger for cancer.

In the following table (Figure 12) popular explanations, including those with which cancer patients do not agree, are expressed in terms of reasons found in the cancer narratives analysed in this thesis. This table does not contain any quantitative accuracy, because my main

	External	Internal
Natural	cigarette smoke, accidents (mechanical injuries), agricultural chemicals used in the 1950s, sun, solarium, contagious diseases, genetics, the Novaja Zemlja nuclear detonation (1961), asbestos, underground water streams, tight clothes/underwear, cosmetics, the Chernobyl catastrophe (1986), polluted rain, poisoned urban air, X-rays, pollution, viruses, electricity	giving birth, losing weight, smoking, hormone treatment, being overweight, food intake, drinking habits, being underweight, lack of vitamins and minerals, getting cold, drinking coffee, one night stands, no children
Psychological	work pressure, marriage crisis, old maid status, loss of a close relative, financial problems, single motherhood	negative thoughts, fear of cancer, sadness, feeling insecure, stress or depression, sorrow, pessimism, inner pressures, hate gathered inside, anger
Behaviouristic	punishment, bad karma, balance for a good life, difficult childhood, war, lifestyle, illness	cancer type, bad nature, personality, self-destructive behaviour, wrong thinking, being too nice, weak nature

Figure 12. Popular cancer aetiology – possible reasons for falling ill

intention is to demonstrate the main ideas characteristic to popular cancer aetiology in modern Finland.

People need to know the primary reason for falling ill in order to rebalance their physical condition and rid themselves of the 'unwelcome stranger'. This kind of reasoning, again, has its roots in history and therefore it is interesting to compare folk medical explanations with modern cancer aetiologies. It appears that if we exclude the 'unclear' category, there are only two common categories: *natural / external* and *natural / internal*, whereas the *psychological* and *behaviouristic* illness explanations represent more the modern way of thinking, affected by evidence or psychological discipline and various neo-religious ideas. It is worth emphasising here that all the categories are to some extent affected by a common idea of personal guilt as being responsible for falling ill (Harjula 1986, 115–135). Therefore, all illness causes become better comprehensible when observed in the context of personal life.

According to the official suggestion of the Finnish Cancer Association, cancer may be caused by inner problems, environmental influences or individual lifestyle. Accordingly, among the preventative suggestions we find advice that one should take care of one's health by practising sports, avoiding the sun, eating healthy food, minimising alcohol intake and checking one's physical condition regularly. The American anthropologist Cecil Helman has proposed that personal explanatory models are marshalled in response to a particular episode of illness, and are not identical to the general beliefs about illness held by a particular society (Helman 2000, 85). Indeed, in their writing, cancer patients use culturally accepted knowledge and interpret it to suit the circumstances of their personal cancer experience. The main problem is that individual experiences, in many ways different from culturally agreed expectations, impact only on the reasoning of a particular person. Consequently, as cancer suddenly becomes an individual challenge, people find it difficult to accept that, despite all individual efforts, they have still fallen ill:

Usein sairauteni aikana pohdiskelin mieheni kanssa, miten oli mahdollista, että juuri minä sairastuin syöpään. Suvussani ei ollut siihen rasitteita, olin aina ollut laihansorttinen, en tupakoinut ja koko lapsuuteni ja nuoruuteni olin harrastanut urheilua. Yleisurheilua, hiihtoa, palloilua – vieläpä ikäihmisenä osallistuin työpaikka-urheiluunkin.

During the times of my illness I often discussed with my husband the reasons for falling ill. How come I fell ill with cancer? In my family there are no traces of cancer, I had always been kind of thin, I did not smoke and I had practised sports my entire childhood and youth. Light athletics, skiing, ball games – even as an adult I took part in sporting activities organised at my work place. (290)

En itkenyt, en huutanut, en särkenyt astioita. Mieleeni tuli sen sijaan juttu, jonka olin jokin aika sitten lukenut jostakin lehdestä. Juttu kertoi suurin piirtein näin: “Kieltenopettajat sairastuvat syöpään todennäköisemmin kuin liikunnanopettajat.” Mutta sairastunut olinkin minä! Minä, joka liikuin ja liikutin muitakin päivät ja illat. Minä, joka en laittanut rasvaa leivän päälle ja söin terveellisesti vihanneksia ja hedelmiä. Minä, josta ihmiset ihmettelivät, kuinka jaksan aina olla niin iloinen ja liikkua niin paljon ja että eikö minua koskaan tympäise vielä koulun jälkeen lähteä pitämään jumppaa ympäri kyliä. Ei! Minua ei todellakaan tympäissytt lähteä ja sanoinikin, että sen takia minuun eivät taudit iskee, kun liikun niin paljon. Geenit – geeneissä se vika on. Ei ole muuta mahdollisuutta.

I did not cry, I did not scream, I did not break dishes. Instead I remembered reading a story from a newspaper. The story went like this: Language teachers have a greater potential to fall ill with cancer than the gym teachers. But I had fallen ill! I had been working out day and night. I did not put fat on my bread and ate healthy vegetables and fruits. Everybody had wondered how I could be so happy and do so much exercise, even after school was over I did not hesitate to give lessons around the village. I was always willing to go and I even told others that I stay healthy because I exercise so much. Genes – there is the problem. There is no other possibility. (121)

These examples demonstrate the need to find the causes of illness. With regard to personal life-course, the meaning of cancer can change several times. After falling ill, and during the illness, patients constantly experience new aspects of cancer. During this process many culturally accepted ideas prove wrong compared to individual experience, and thus people negotiate their own illness model based on their own life stories.

Culturally accepted ideas are less flexible, and thus popular cancer discourse stays unchanged. This kind of stability is characteristic to any set of popular beliefs and is connected with the process of communication. When individual experience (personal voice) is in opposition to popular reasoning, communicative acts such as composing a narrative, force people to maintain the culturally pre-set beliefs framing the

discourse. Thus, when debating the origin of illness, or other illness related beliefs, respondents in fact repeat culturally accepted beliefs and thus reproduced them in their narratives. Therefore, I suggest that even if marshalling individual explanations towards culturally approved explanations, all respondents actually select an aetiology appropriate and acceptable within their own life from among the existing explanations.

Natural external and internal causes

The *natural/external* category includes dangers from the environment that influence people's health by attacking from outside. This category is foremost connected with political and economic decisions made in past decades affect the Earth and its ecosystems (see articles in RACHEL Environment & Health Weekly; see also *Rachel's Daughters* 1997, a movie by Nancy Evans). Among the explanations we find polluted air, sunlight, tanning beds, radiation, underground streams, clothes, cosmetics, and also genes and viruses. In the beginning it is perhaps difficult to understand how these very different factors may belong to one category. Therefore I once more point out that my aim is to track popular reasoning from an ethnomedical perspective. As I go through these explanations I compare these ideas with thoughts deriving from folk medicine presented in the previous chapter. This is to point out the major changes affecting popular ideas about cancer's origin and the changes in these ideas over time.

The 'bad air' or miasmatic explanation (for example wind from the north, poisonous air from the swamps, etc.) belongs among the most ancient illness explanations (Porter 1999, 10). With modern cancer aetiology bad air refers to polluted city air (246, 381, 512), radioactive tests, the Novaja Zemlja (1961) nuclear detonation and the Chernobyl (1986) nuclear catastrophe, chemicals used in agriculture and the building industry (11, 54, 43, 103, 196, 197, 256, 542). Associating the origin of cancer with bad air is a new phenomenon and therefore needs to be explained here. If polluted city air and the use of chemicals are the results of modern life, cigarette smoke helps to exemplify the diachronic change of popular thought rather well. In folk medicine, tobacco and tobacco smoke have been used to soothe pain and as part of various remedies. The ongoing work on the negative effects of smoke and smoking has caused a change in popular reasoning, so that today

cigarette smoke is one of the best known causes of (lung) cancer (2, 24, 28, 51, 86, 224, 236, 265, etc.). According to respondents' explanations, pollution substances responsible for cancer may also be hidden in badly fitting clothes (tight jeans and restrictive underwear, 190) or man made materials (197), and also in cosmetics and similar products (such as deodorants, 229). In this sense culture-based illness aetiologies have not changed, although the substances have. People still tend to believe that illnesses are transmitted within mediating agents.

With regard to harmful substances, several changes in cancer patients' reasoning are fascinating to follow. For example, according to ethnomedical records, fire could be interpreted as a cause of cancer, while today fire is replaced by sunlight or the solarium (38, 56, 559), although perhaps X-ray treatments (337, 512) and electricity cables close to the household (45, 572) may also be interpreted in ethnomedical terms as the modern version of 'endangering fire'.

The belief that earth is responsible for falling ill seems to be entirely forgotten, at least when it comes to touching, sitting on or walking over the ground. This appears to be a more general trend, which may be explained by the fact that modern Finns do not normally have such a close relationship with the ground as rural Finns did, and thus the dangers coming from touching earth are simply irrelevant (Kivari 2008b). On the other hand, underground streams (185) being responsible for cancer certainly belongs to the category of 'harmful earth' energies. It is interesting to note that these streams were also recognised among German cancer patients as a reason for falling ill (Schwibbe 1989, 51–52).

Perhaps the most fascinating question concerns what happened to the disease worm image. I would suggest that this has been replaced, because of the development of medical awareness, by viruses and bacteria (38). A similar phenomenon has taken place in dentistry, where disease worms causing pain have been replaced in modern Finnish folklore by *hammaspeikko* (lit: 'dental troll') bacteria in both child and adult imaginations (Pekkola 2010). In a similar way to the disease worm image, viruses represent living beings that attack from outside and cause illness.

Unfortunately, there is no real certainty as to what kind of images modern gene theories have evoked in human minds, although despite this genes too are now 'accused' of responsibility for cancer (see 96, 121, 179, 401, 412, 462, 600, etc.). In the ethnomedical sense popular

gene theories could be interpreted as modern constructions of illnesses caused by dead ancestors, which has been a very common illness explanation in Finnish folk medicine (Waronen 1898, 17). However, as interesting an idea as this is, investigation and proof must be undertaken by another researcher as the emphasis of this thesis lies elsewhere.

The *natural/external* explanation for cancer entails it being seen as a contagious illness (31, 33, 76, 79, 157, 160, 164, 205, 401, etc.). This does not mean that people believe that they have caught cancer from someone else, rather that this view refers more to the social fear of others: *Tunsin olevan leimattu, kuin raamatun spitaaliset*, "I felt myself labelled as the leprosy patients in the Bible." (646). From the pathographies it is apparent that people continuously sense that those without cancer are afraid of them and wish to keep their distance. In the cancer patients' writings the idea that cancer is contagious represents a common-sense explanation and is strongly connected with the idea of being labelled by cancer. From the ethnomedical point of view this kind of control is foremost connected to the culturally approved attempts to 'protect' healthy society members (Honko 1960, 57–61).

Dominant among the *natural/internal* explanations are various rational causes dependant on the body possibly becoming more responsive to cancer. We can see some interesting differences when compared with rational illness causes extant in other folk medical systems. The period of modernisation and the construction of the welfare state signified big changes in hygiene in Finnish homes (Helén & Jauho 2003, 24). In addition, bad clothing – according to modern folklore – or its lack, is no longer an issue, but rather more likely is the quality of clothes, as mentioned above. Other universal health issues, such as food intake, alcohol abuse and smoking habits have continued to be problematic in Finland. As these themes are continuously discussed in public, people are aware of the risks that unhealthy eating, drinking or smoking may bring, although respondents to the writing competition seem to deny that they have been eating unhealthily or drinking too much. In my opinion, this denial could above all be explained by the average educational or professional level of participants.

Unlike eating or drinking, all respondents to the writing competition accepted that smoking is a dominant cancer cause. Lifelong smokers admit that their cancer could be a result of this habit, as do passive smokers:

Syön paljon vihanneksia. Kalaa kerran viikossa, lihaa ei tuolloin oikeastaan ei koskaan. Aamuisin juon aina itse-puristettua greippi-appelisiinisitruunamehua. Elin niin terveellisesti kuin saatoin. Tupakka en ole koskaan polttanut, mutta olen kyllä joutunut passiivisen polttajaan asemaan sekä työpaikalla että sairaalassa viedessäni miestäni tupakahuoneeseen.

I eat lots of vegetables. Fish once a week, at that time I ate almost no meat. In the morning I always drank homemade grapefruit-orange-lemon juice. I lived as healthily as I could. I have never smoked, but I have been in the position of passive smoker, both at work as well as in the hospital when taking my husband to the smoking room. (024)

At first glance the habit of drinking coffee (28, 543, 572) could be classified as a modern health concern, in the same way that tobacco was said to have positive affects on health in the past. However, the difference is that drinking too much coffee has never been seen as a healthy habit. At least in the Finland the negative affects of coffee overuse were discussed rather early (see for example Waerland 1949, 82). Compared to smoking, which was considered healthy in folk medicine, the bad feeling caused by too much coffee was perhaps more graspable (immediate impact) than the possible harm caused by smoke (slow impact), which in the very short term was soothing to nerves and reduced pain. Despite information regarding the negative impact of coffee, people cannot stop drinking it because it brings joy, and also because drinking coffee is one of the most important social activities among Finns:

Mutta elintavat... Olen aina ollut huolehtimaan terveydestäni, ennen vitamiineihin ja hivenaineisiin tutustumista. En kovinkaan paljon piitannut liikunnasta. Söin todella huolettomasti, useimmiten korvasin lounaan kahvilla ja leivoksella. Olin oikea kahviratti. Siihen saakka, kunnes hivenainelääkäri kertoi, että kahvi sisältää tuhat erilaista myrkkyä ja rientää viidessä minuutissa nauttimisesta rintarauhaisia ärsyttämään. Olisiko siis kahvi kaiken pahan alku ja juuri? Kahvista en kuitenkaan ole vielä kukaan kokonaan osannut luopua. Jotain nautintoja täytyy sentään itselleni sallia! Muuten on taas jo lähellä sairastuminen – askeettisesta ikävästä elämästä johtuen!

What about my habits... I had always been bad in taking care of my health before I learned about vitamins and minerals. I did not like to do much exercise. I ate carelessly, often replaced lunch with coffee and cake. I was a true coffee addict. At least as long as the mineral doctor told me that coffee contains thousands of different poisons and five minutes after enjoying it goes to annoy glands in the breast. Could

coffee be the grounds for and root of all that bad? However, I have not given up coffee entirely. Some kind of joy one has to allow to oneself! Otherwise one would be again close to falling ill – caused by an ascetic and boring life! (572)

If the other causes of illness mentioned in the *natural / internal* category are connected with serious illnesses in general, then the idea that cancer is the result of vitamin and mineral deficiency (288, 290) highlights the new trend in alternative and complementary medicine. According to the cancer narratives, this trend was introduced to Finnish cancer patients in the 1980s and is also present in modern cancer discourse. The second cause connected with (bio)medical discourse on cancer is the use of oestrogen or other hormonal treatments among menopausal women. Respondents (9, 130, 214) believe, or at least suspect, that their illness could be somehow connected with consuming medicine prescribed by doctors.

In a similar way to other rational reasons, losing or gaining weight has for a long time been thought to show underlying symptoms that might raise health concerns. This has gained a new meaning because people are now concerned about their weight mainly because of the culturally agreed norms that guide us towards the modern version of the aesthetic body (Kinnunen 2008, 307–321). This means that some people use lots of energy to control their bodies, while at the same time consuming a great deal of unhealthy food, whereas others stop eating for periods in an attempt to balance their health, sometimes putting the body under great stress (Puuronen 2004, 80–83). Within the modern body-conscious cultural context one should bear in mind that in cases where respondents wrote that they have always been ‘overweight’, this foremost refers to their subjective body image, built on the (perceived) expectations of society.

Following on from this, other societal expectations are also detectable in modern cancer aetiology. Unlike hurting oneself (25, 53, 461, 538, 555, 572, 604) or getting cold (508, 524, 604), some of the causes are obviously sensed as tools of soci(et)al control. Having children too young (277), having too many children (2, 133), or none at all (177, 250, 292, 318, 412) represent individual risk behaviours, which from the societal point of view could be taken as problematic. Having too many one night stands (511) is also interpretable as acting against societal expectations, and in doing so weakening the human body and its resistance abilities (331). The fact that people connect the origin of

their cancer with these particular issues demonstrates that they are well aware that acting against socially set norms (normal behaviour) brings punishment, and that the punishment may occur in the form of illness.

These beliefs are also interpreted the other way around, which for cancer prevention work is even more significant. Folk beliefs that, for example, young mothers or women without menstruation do not get cancer, stop people going to a doctor and receiving the right diagnosis when the first signs of illness occur:

Vihdoin suustani tulivat sanat: "Oliko se sitten syöpää?" Olinhan minä sen koko ajan tiennyt, mutta olin sen niin onnistuneesti sulkenut ulos ajatuksistani. Miten vastenmielinen sana tuo syöpä oli juuri minun kohdallani. Kyllähän jollain vanhalla ihmisellä voi syöpä olla, mutta että minulla, nuorella naisella – minullahan oli vielä niin pienet lapsetkin – minunhan pitäisi olla vahva ja suojella lapsiani. Lääkäri vastasi, että syöpähän se oli.

Finally, words came out of my mouth: "Is it a cancer?" Well, I had known it all the time, but I had succeeded in closing it out of my mind. How disgusting was the word cancer. An old person can have cancer, but I, a young woman – my children were still so young – I should be strong and protect my children. The doctor answered that cancer it was. (088)

Above all, the natural explanations listed above should be interpreted and understood as internal or external causes which, according to popular knowledge, 'trigger' cancer. Even those respondents who argued that no one really knows what actually causes cancer (see also Schwibbe 1989, 51), believe that certain 'triggers' set off cancer at particular times in a person's life. Therefore *natural / internal* and *natural / external* causes may be interpreted as 'triggers' that break through the individual's immune system, allowing cancer the opportunity to gain control over the body.

The process of searching for appropriate coping methods is foremost psychological. As an important part of the inner negotiation process it forms one of the most central issues in cancer narratives. Accordingly, sufferers carefully examine their life history in order to detect the possible reasons for falling ill. During this process the respondents used multiple methods of self examination. They look for psychosomatic and external influences and employ other culturally accepted explanations, such as punishment, contagion or genetics. This kind of culturally shared approach to individual illness represents, in fact, an ancient

mythical thought: in order to cope with one's illness and aim for a successful cure, one must be aware of what possibly caused the illness.

Psychological and behaviouristic causes: downtrodden women and 'go-getter' men

In a similar way to natural illness causes, psychological and behaviouristic illness causes also mediate the expectations and concerns of society. In addition, it is also noticeable that in the Finnish context these particular illness causes are very much affected by ideas deriving from health psychology, and are affected by new religious movements such as Buddhism (60, *paha karma*, bad karma) and other mind and body maintenance techniques. As expected, the individual, with his or her characteristics, daily struggles and unsolved problems can be placed at the centre of this nexus. However, the modern setting is to some extent different from the times when folk medicine represented the dominant healing discourse for Finns. An illustration of how that change is important comes from the fact that illness is no longer diagnosed and treated in the domestic sphere. As I pointed out above, modern doctors and patients do not share illness meanings based on sense experiences. By which I mean that when entering hospital, individual work pressures (15, 100, 232, 233, 265, 331, 339, 423, 441, 543, 566, 648, etc.), marriage crises (46, 227, 334, 421, 566, etc.), loss of a relative, sorrow and grief (188, 373, 375, 545, 596, 612, etc.) as well as financial problems (233, 543, 573) must be left behind, as the individual's daily troubles are excluded from biomedical treatments; even hospital psychologists tend to overlook these concerns (Crossley 2008, 21). When compared to the modern medical paradigm, this kind of personal concern was more to the fore in folk medicine when negotiating the illness origin and aiming for recovery.

When introducing the behaviouristic and psychological causes of cancer I decided to concentrate on two types of descriptions, which, within the context of the cancer narratives, could be called short psychohistories. The first kind of psychohistory mediates the belief that some people have a *syöpäpersoona* (cancer personality) or that they are a *syöpätyyppi* (cancer type). The latter suggests a possible connection between cancer and something that could be described as the *menevä* ('go-getter') lifestyle. These ideas should by no means be separated

from each other. These ideas are intimately connected to individual behaviour, ways of thinking and everyday action, and therefore the available written illness reconstructions contain a large amount of individual variation (see also Siikala 1991, 80–86).

The cancer personality concept stems from the culture-bound idea that cancer is the result of certain kinds of individual (mis)behaviour. According to this, people are made responsible for falling ill, either by acting or thinking in an improper manner (79, 87, 195, 339, 475, 533, 563, etc.). This kind of evaluation is again based on the culture-bound expectations that form the setting in which 'normal' is formed of culturally agreed behaviour and thinking. Finns describe an individual with a cancer personality as a person who denies individual desires and puts others ahead of him- or herself:

Kun oikein ajattelen, niin olen juuri tuollainen tavallinen syöpätyyppi. Aina valmis joka paikkaan ja usein tekemään enempi kuin tahdon jaksaa. Heikko itsetunto ja omantunnontuskia poteva.

If I think about it, I am exactly this kind of ordinary cancer type. Always ready to participate and make more than one actually can. With low self-esteem, and suffering from poor self-image. (031)

The cancer personality explanation is foremost based on the idea that cancer is triggered by particular psychosomatic conditions, which are additionally influenced by multiple external challenges such as being a single mother (573) or an old maid (140, 177). Respondents also write about the common belief that negative thoughts (33), a pessimistic nature (409) or self-destructive ideas (289) can be interpreted as causes of cancer. Of course, in cancer narratives these causes become interpreted and represented in numerous ways. Adopting these culture-bound explanations may even lead to self-accusation:

Sitten aloin miettiä mikä oli saanu kyhmyn muuttumaan. Mitä mä olin syönyt tai juonut väärää? Milloin muutos oli alkanut tapahtua? Oliko remontin aineksissa ja työssä jotain herkistävää ja rasittavaa? Onks mun mieleni saanu tän aikaan? Mähän olen tällanen helposti masentuva, yksinäinen murehtia, joka muutenkin hautoo synkkiä ajatuksia. Ja kuinka pitkälle taas tänkin masennuksen juuret ja syyt johtaa.

I began to think about what had made the bump change. Did I eat or drink anything wrong? When did this change begin? Was there anything in the materials I used when renovating that I was allergic to, or something exhausting about my work? Has my mind caused it? I am this kind of person who is easily depressed and worries alone as

a matter of fact, dealing with dark thoughts all the time. And how far away actually are the roots of this depression. (087)

People find it annoying that the cause of their illness is often seen as personal misbehaviour. On the other hand, by putting these beliefs on paper they perpetuate them, even though their primary intention is to deny these ideas:

Mieleeni tuli kysymys, olenko itse hankkinut tämän sairauden. Joku oli aikoinaan sanonut, että elämäni on itsetuhokäyttäytymistä. Elämänrytmilläni tuhoan elämäni. Nyt oli käynyt näin! Mutta torjuin itsesyytökset: kaikki se, mitä olin kokenut, miten olin elänyt, oli ollut rikkasta elämää. Juuri niin minun oli pitänyt elää, saadakseni kokea sellaista elämän rikkautta. [---] Olinhan saanut kokea melkein kaiken sen hyvän, mitä elämä voi antaa. En voinut syyttää itseäni, en katua elämäntapaani.

I asked in my mind if I am personally responsible for this illness. Someone had once said that my life is a self-destruction. That with my life rhythm I destroy it. Now it has happened! But I denied all self-accusations: all that I had experienced, how I had lived, had a rich life. That was exactly the way I had to live my life to experience all this richness of life. [---] I had experienced all the good things life can give. I could not blame myself, or regret my lifestyle. (160)

Comparing female and male stories reveals an interesting split between the sexes' attitudes on the idea of the cancer personality. Namely, female respondents seemed to adopt popular explanations about depressive personalities as the cause of cancer more frequently than male. Male cancer patients claimed that the reasons for falling ill are connected with their nature and behaviour as *menevä mies*, which can be translated into English as 'go-getter'. This gendered difference made me pose two questions: firstly, what meaning does *menevä mies* have in Finnish language and culture, and secondly, does the use of such a concept affect cancer patients' illness experiences? The second question was, again, inspired by Arthur Kleinman's statement that finding a proper explanation for falling ill may be seen as the first step towards coping with illness (Kleinman 1980, 104).

The available materials gathered via the writing competition contained numerous responses from breast and gynaecological cancer patients, and this suggested an examination of the ideas of prostate cancer patients in order to find answers to my questions (037, 173, 220, 346, 403, 501, 508, 534, 562, 669; see also 110, 157, 305, 406, 470, 509, 569), although, the concept of *menevä mies* is also used by other male

respondents and in writing *about* male cancer patients. Unfortunately, the narratives collected in 1994 demonstrated that it was difficult for men to discuss their prostate cancer openly as it was perceived to be an embarrassing topic (see also Chapple & Ziebland 2002, 826–827):

Mutta mikä on syövässä sellaista, että sitä on vaikeampi tunnustaa kuin esimerkiksi sydänvikaa, mahahaavaa tai vaikkapa eturauhasvaivaa. Syöpä on kuin mielisairaus, sukupuolitauti tms, joka pyritään salaamaan, vaikka siitä paranisikin lopullisesti, kuten minun kohdallani nyt on käynyt. Ei ole syytä ylpeillä tai leikkiä sankaria, vaikka voittaa näin vaikean sairauden.

What is it with cancer that it is more difficult to admit than for example heart failure, a peptic ulcer or even problems with the prostate? Cancer is like a mental illness, a sexually transmitted disease, etc., which everyone tries to hide, even if one could be healed from it, as has happened to me. There is no reason to be proud or play the hero, even if one conquers such a difficult illness. (650)

In order to gain more evidence on the subject it was necessary to search for answers in Internet forums that cater for cancer patients. Comparisons between the written cancer narratives and current discussions in these forums showed that today, instead of hiding their illness, men have found ways to discuss their illness experience more openly. In comparison with 1994, public discussion about prostate cancer has become a daily subject in the Finnish media. Cancer support organisations organise public meetings in which various issues relating to prostate cancer, such as testing, screening and treatment, are openly discussed. However, it is not clear how openly men discuss their illness with their families, friends or colleagues, as having cancer still carries a strong culture-bound stigma to which men may be more susceptible than women.

To begin with, I questioned my Finnish colleagues and friends to clarify the meaning of *menevä mies* in cancer discourse. Here are some of their spontaneous answers:

- an active man, who is not mouldering at home. Has some negative connotations relating to activities connected with bars and females;
- it has many meanings depending on context. It can mean a sporty or active man, the wife may nag that her husband is never at home and is thus a *menevä mies*, it may refer to someone who feels good in bars, as well as having some connotations about sexuality, although the latter is however not so important;

- I just asked around here and it seems that most people interpret it as something positive, e.g. active, business oriented, ready to participate in different things;
- regarding illness, *menevä mies* may refer to the fact that the man has not been concerned about living healthily, but has “burnt the candle at both ends”. Not necessarily sexual;
- yes, not sexual, but a flirting man may also be a *menevä mies*.

Accordingly, the *menevä mies* concept includes a socially active man who does not take care of his health. The concept is mainly regarded as positive. The negative connotations relate to social activities associated with spending time in bars and coming into contact with numerous women. However, *menevä mies* does not necessarily refer to someone who is sexually active. These explanations are required mainly to understand the following discussion about the idea of the go-getter lifestyle as a trigger for prostate cancer.

As a next step, I introduced a statement and question for discussion in the cancer patients’ forum in the *miesten syövät* (male cancers) section, as follows:

- “Many people argue that cancer is a result of a particular personality. I have heard that prostate cancer is recognised as an illness of the *menevä mies*. What does this actually mean?”

The first answer I received was that this is *huuhaa* (‘total crap’), similar to the belief that cancer is result of a sinful life. Although the answer was not polite, I was really glad to receive it because respondents discussed the connection between cancer and ‘sinful life’ rather often in the cancer narratives. In several answers people referred to nonexistent medical evidence in this connection. This kind of attitude towards the origin of cancer was no surprise to me. I have followed Internet discussions for several years and, if religion-based discussions are excluded, it is rare for someone to dare to discuss something that could be interpreted as alternative or non-scientific. Whereas the cancer patients’ writings that I analysed offer ethnographic insights into the popular reasoning on cancer, the cancer forum deals with cancer patients’ acute issues, such as the meaning of a diagnosis or the effect of a medicine. In the Internet forum, people also share the newest evidence-based medical results and discoveries on cancer. This is because the forum discussion is supported and moderated by cancer support organisations representing scientific medical discourse. Thus,

the Internet forum is more for discussing cancer according to the medically proven paradigm.

One man wrote that he had met some men who have prostate cancer and based on this “evidence” he suggested that there were all kinds of men with different lifestyles among them. However, he noted that perhaps those men with so-called ‘go-getter’ lifestyles are otherwise more open too, and talk about their problems in public more easily.

With Finnish men, this concept refers to something that again becomes understandable in the broader socio-historical and cultural context. If female cancer patients claim that cancer is a result of underestimating themselves and suppressing individual desires and needs, then in male cancer patients’ stories overestimating individual power and state of health becomes dominant. The *menevä mies* concept, with its positive and negative connotations, also implies risk behaviour because, within this paradigm, men do not care for or pay attention to their health. It mediates the (desired) active male role in society as well as the insignificance of an individual’s health for those who exploit this role. And when illness occurs, using the concept of *menevä mies* is a culturally acceptable way to search for salvation and cope with the situation.

With this selection, I wished to demonstrate that according to popular cancer aetiology, depression and optimism may equally lead to falling ill with cancer, which again proves the unpredictable nature of this illness. The folk beliefs about cancer that are represented in the cancer narratives, above all mediate that health and illness are affected by biological, ecological, behaviouristic and social conditions, all of which affect the individual. Accordingly, psyche cannot be separated from soma (Dalton et al. 2002, 1322). Because of culture-bound reasoning people are aware of various illness causes typical to cancer, but while mentally negotiating these causes they merge the causes with their own life stories and thus some of the reasons gain more significance than others. When dealing with narrative self-expression, an individual’s expressive skills, and particularly the selected narrative tendencies, should not be overlooked in order to understand what is going on.

The vulnerable position of the cancer patient

As people communicate on health issues they share their culture-bound ideas. These ideas are examined critically and not necessarily held to be true. However, it is important to keep in mind that all kinds of conversations (including inner dialogues) are connected to our culture. Therefore it is important to be aware of the culturally adopted health beliefs and communications that mediate and represent culture-bound understanding. Where social constraints are set on a particular discourse, as appears to be the case with cancer (Lepore & Revenson 2007, 313–314), ideas expressed in writing become even more significant. Above all, comprehension of such culturally pre-set expectations helps us understand and interpret the individual challenges that face people with cancer.

Before falling ill, people admit to being afraid of cancer (38, 102, 335, 350). However, the cancer diagnosis places people in an entirely new situation. From an individual point of view this means that people realise their life is suddenly endangered. For individuals, having cancer means that a human being will be placed in a different time and space dimension, which British journalist Susan Sontag has described as falling out of this world, that is to say “emigrating the kingdom of well” (Sontag 1978, 3). Having cancer also means that the illness experience divides the individual life course in two: before and after, although such division is possible only in event-based interpretations, such as narrative self-expression. The changed situation signifies the beginning of a process that has a lot to do with identity alteration: losing and finding oneself.

Loss of self happens quickly as people are pushed outside 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. 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 assures 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 the physical concerns, serious illness also causes people to be confronted with eco-

conomic and social problems that exclude them even further from 'normal' life, leading to psychological challenges (Hayes & Nutman 1981, 14).

Illness changes the individual's position in society, but it also changes their surroundings. Family members, friends and work colleagues are equally confused when unexpected illness strikes. For many it means that they do not know how to behave or what to say. Quite often such uncertainty is based on culture-bound fears and erroneous beliefs. In such situations people in the social circle around a cancer sufferer often decide to avoid the subject, or even the person, which again affects the person's condition in a negative way:

Kyllä ihmisten kohtaaminen kumminkin muuttui, tilanne oli joidenkin kohdalla samanlainen, kun kuoleman kohdanut ihmisen lähestyminen on joillekin, minullekin vaikeaa. Ystävät kyselivät vointia, ottivat ja elivät mukana, lohduttivat, mutta toiset pelkäsivät minua, ja sen haistaminen oli minulle vaikeaa.

Seeing people was different [in comparison with before]. Some acted as before, for others, also for me, it was difficult to see someone who had faced death. Friends asked how I felt, and sympathised with me, but others were afraid of me and this was hard to handle. (015)

En oikein tiedä mitä olisin halunnut heidän sanovan; kaikki saamani myötätunnon osoitukset kolkuttivat omaatuntoani, ja hiljaisuus ja välipitämättömyys loukkasivat. Paras oli varmaankin se, kun he kysyivät, että miten itse suhtaudut asiaan. Tätä kautta pystyin puhumaan omista tunteuksistani heille ilman huonoa omaa tuntoa.

I do not really know what I expected them to tell me; all condolences I received made me self-conscious, and silence and ignorance did hurt. The best was perhaps when they asked what I thought about it. In this way, I could share my feelings without becoming self-conscious. (531)

The popular image of cancer is closely connected with death and dying, and thus, often at the societal level, people with cancer are treated as 'fading'. This particular image of cancer influences expectations of the cancer patient's behaviour. According to culturally accepted ideas, people with cancer are expected to pass away shortly after the cancer is discovered. Thus, those with the disease are expected to act and look differently to 'normal' people. Indeed, social expectation of illness behaviour encompasses even the patient's appearance. If a person looks too good, society may refuse to believe that they are suffering from cancer. According to societal expectations, cancer patients should behave like dying people and therefore be excluded from daily activities: they

should not work, they should not enjoy life or follow the daily news. Taking part in activities considered inappropriate for cancer patients might even insult others – those who are ‘normal’:

Olin jossain tilaisuudessa, kuulin keskustelun eräästä henkilöstä, joka oli tanssimassa “tuokin on täällä tanssimassa vaikka sairastaa syöpää?!” Silloin olin vähällä mennä heiltä kysymään “miksi ei saisi olla pelkäättekö että tarttuu? En voinut mennä, sillä olin niin loukkaantunut sen henkilön puolesta vaikka en häntä tuntenutkaan lähemmin, tiesin kyllä että hän todella on samassa “veneessä” kuin minäkin, sillä kai se kosketti niin läheisesti – silloin vaikka joku sanoo ymmärtävänsä miltä tuntuu sairastua syöpään – uskallan väittää, vain hän tietää, kuka tämän sairauden uhri on, että miltä se todella tuntuu!!”

At one party I heard a discussion about someone [with cancer] who was dancing. “Look, even this one is dancing?!” I was about to go and ask: “Why shouldn’t she, are you afraid that you’ll catch it?” I could not go because I was so hurt, even though I did not know this person personally. I knew that we were in the same boat, perhaps that’s why it hurt me so badly – even if someone tells me they understand what it feels like to have cancer, I dare to claim that only victims of that illness know how it really feels!! (240)

It appears that when a person announces that they have cancer, society begins a process of management relating to the sufferer’s behaviour and appearance. Conclusions, as well as (mis)judgements, are made according to each individual’s understanding as outlined by culture-bound ideas relating to the particular situation. If the sufferer acts ‘unnaturally’, by not following cultural norms appropriate for cancer patients, ‘normal people’ feel threatened. Sometimes the popular image of cancer affects behaviour so intensely that some people still do not hesitate to break their social connections with those who have cancer:

Pääsin takaisin työelämään. Olin ollut työtehtävissä, jossa jouduin koskettelemaan asiakkaitani! Oli hoitotyössä. Olin avoin ja kerroin syöpäleikkauksestani! Jotkut suhtautuivat asiallisesti, mutta monet hyvin ennakkoluuloisesti ja pelko paljastui erään asiakkaan sanoessa: “Syöpähän tarttuu, en sitten tule enää hoitoon!” En tiennyt, että näin voimakasta ennakkoluuloa on vieläkin! Oli muitakin, jotka jättivät tulematta luokseni pelon tähden! Syöpä – ruttotauti! Voi, miksi en osannut pitää suutani kiinni!

I was back at work. Because of the nature of my work [massage] I had to touch customers! I was a nurse. I was open and told them about my cancer surgery! Some took it calmly, but others had prejudices

and were afraid. One customer told me: "Cancer is contagious. I will not come to you anymore!" I did not know that such strong prejudices exist today. There were also others who did not return because they were afraid! Cancer – a plague-disease! Alas, why could I not keep my mouth shut! (079)

It is not unusual that in addition to the patient, community members will also ask: 'What has she or he done wrong to be punished in this way?'

Koska paikkakunta oli pieni, missä asuin, tieto sairaudestani pääsi kuitenkin leviämään. Jos missä kuljin, niin ihmiset tulivat puhumaan minulle, että miten se on mahdollista, että sinullekin se voi tulla, koska liikut paljon, et polta, et juo alkoholia jne... Jopa kotiin soiteltiin ja kysyttiin.

As I lived in a small town the information about my illness began to spread. Wherever I was people came to talk with me and wonder: How is it possible that you got it, you work out a lot, you don't smoke, nor do you drink, etc... They even called me at home and asked. (091)

This kind of judgement made on a societal level may, again, cause intolerance towards sufferers. Possible answers to this question are typically found within the personal life story, as I demonstrated above. In some situations, however, it is difficult to define the faults of the sufferer, and this becomes particularly complicated when the cancer patient happens to be a child or youngster. Consequently, parents or even grandparents may become the stigma carriers as potential norm-breakers:

Miksi kohtalo on näin epäoikeudenmukainen? Miksi optimistinen ja elämänhaluinen lapsi saa kärsiä? Rakas viaton lapsi. Sairaus on synnin palkka, sanovat jotkut. Rangaistus. Mutta kenen synti on niin paha, että viatonta rangaistaan? Minun vai Paavon vai jo edellisten sukupolvien? Jos kysymys on rikoksesta ja rangaistuksesta, niin mielestäni viattoman lapsen rankaiseminen on rikoksista pahin.

Why is destiny so unfair? Why must an optimistic and lively child suffer? Dear innocent child. Illness is punishment for sins some people say. A punishment. But whose sin is so bad that the innocent one is punished? Is it mine or my husband's, or does it come from previous generations? If the question is about crime and punishment then I think that punishing the innocent child is the worst crime of all. (402)

The dominant beliefs that underline 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. 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 both cope with the idea of being ill and with the search for possible ways out. According to the cancer narratives, 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, and accordingly every lived moment becomes more significant than previously.

Conclusions

In this chapter I have argued that cancer discourse, a culturally complicated phenomenon, is defined by three significant aspects relating to the disease. The first aspect affecting reasoning on cancer is socio-historic development. Accordingly, cancer is identified as an incurable illness causing pain and suffering and leading sooner or later to death. This image derives partly from the folk medical context in which, historically, people were incapable of diagnosing and treating cancer; and partly this view relates to cancer's biologically uncontrollable nature. This second aspect has led in part to the stigmatising image of cancer. An image that is connected with fear and uncertainty and which is shared by all sectors of society. According to popular reasoning, cancer is believed to be contagious. The other equally strong socioculturally agreed belief sees cancer as a punishment for some kind of norm-breaking. The third reason concerns cancer's complex nature as an illness. Cancer has multiple forms and therefore it is difficult to recognise the symptoms, and extremely challenging to propose suitable preventative methods. Thus, for cancer patients, culturally agreed cancer discourse contains numerous possible interpretations and definitions of the internal and external reasons for the triggering of the illness.

The cancer narratives analysed in this work support Mel Greaves' suggestion about the uniqueness of cancer. Based on these narratives, every single cancer case may be seen as the complex outcome

of internal, external, natural, psychological or behaviouristic causes connected with the individual's life. Every time cancer occurs the situation or the setting is new, and therefore the individual's reasoning on possible aetiologies, as presented in the cancer narratives, is full of various illness interpretations. Therefore, to distinguish popular ideas on cancer aetiology is a challenging task. Its complexity lays mainly with respondents' heterogeneous attitudes towards the represented beliefs. In their narratives cancer patients may agree with popular explanations or deny them; however, debating the origin of cancer is a significant theme in cancer patients' writing. Popular reasoning about the onset of cancer also explains why, within the cancer narratives, it is so important for sufferers to find reasons for their illnesses.

In this chapter I have demonstrated that when composing their narratives, the respondents were confronted with culturally preset beliefs that frame cancer discourse. In their writing, people explain their illnesses from the personal point of view, taking their own life course into consideration. After they are diagnosed with cancer they go through a private dialogue involving the socioculturally agreed understandings of the internal and external aspects that might have triggered the cancer. In order to explain the onset of their illness, they search for aetiologies that match their own lives. The most commonly accepted aetiology makes people individually responsible for falling ill. Although many cancer patients do not agree with this assumption in their writing, they point out that cultural uncertainty about cancer's origins labels patients and makes their position particularly vulnerable in everyday life.

WRITTEN CANCER NARRATIVES

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