

## 7. Patients' Feelings About Deficiencies in the Biomedical Healing Drama

Illness has never been exclusively an individual problem. Individuals, and the society in which they live, understand illness as a social crisis that must be solved quickly using all available knowledge (Honko 1993, 523). Therefore, in every society a fixed social setting exists for human behaviour when a person falls ill. Within this social setting the moment of diagnosis becomes a marker for the beginning of a pathological drama. In an ideal case the pathological drama or illness process lasts until the illness is cured and the person is declared healthy again. Unfortunately, having cancer does not fit in the category of normal pathological drama.

New diagnostic techniques, such as X-ray screening, CAT scans (Computerised Axial Tomography), ultrasound and MRI scans (Magnetic Resonance Imaging) have brought advantages in the early detection of cancer. In some cases diagnosis saves lives, however the problem is that these diagnostic advantages have outstripped the cures. According to Roy Porter, despite numerous victories in the biomedical field, no 'magic bullet' has ever been found to cure cancer: surgery, radiotherapy and chemotherapy offer relief far more often than a cure (Porter 1999, 576–578; see also van Helvoort 2001, 33–60). Although cancer survival rates have increased rapidly over past decades (see Finnish Cancer Registry, Newest survival rates) there is still too little information about how cancer patients themselves feel during the biomedical healing process and how they actually 'survive' their illness. I emphasise that under such conditions, where the final outcome is rather uncertain, it is very important to offer cancer patients all kinds

of support to improve their condition. This suggestion is based on the cancer patients' narratives that indicate the situation is somewhat problematic in modern healthcare centres. The main criticism considers the occasions when patients are handled as medical cases or diseased bodies, and are left without individual support from the doctors' side. Based on my material I suggest that the more human approach is an important goal that doctors should be working towards for a more satisfactory outcome.

Adopting the patient's role means that people are forced to go through socially approved 'rites of passage' in order to become well again. Biomedical treatments given in hospital are attempts to stop cancer cells from destroying the human body. According to cancer patients' descriptions, the treatments may be so vicious that they change a healthy person into one who is suffering. This means that patients lose control over their bodies. Regarding chronically ill and terminally ill people, Cheryl Mattingly has suggested that "when illness is protracted, when there is no hope of being 'normal', a person's very sense of *self* is lived in a special way through the body. Personal identity becomes intimately tied to the pain, uncertainty, and stigma that come with an afflicted body." (Mattingly 2004, 73) Cancer patients, and those who are made temporarily ill by medication, find themselves in a rather similar situation. Even if the personal condition turns for the better and the connection with a person's own body grows stronger, it is difficult to get rid of the images of the self as some kind of "diseased being" (Soivio 2003, 110). Therefore, the individual experiences gained through the officially approved healthcare institutions are described as significant and challenging when we consider the individual illness process in terms of becoming well. In their writing, cancer patients express the view that the biomedical treatments offered by society are not enough to become well. People crave holistic attention because they perceive that this would unite treatment of the body with an individual's emotional needs.

The individual challenges people face as patients in the cancer clinics describe the changes in the individuals' position while in the role of cancer patient. Even if people get used to hospital rules and routines, the time spent in hospital represents a period of losing control over one's life. Furthermore, cancer patients' narratives say that when treated under such uncertain conditions it is difficult to trust physicians, particularly because communication between physician and

patient is often built on silence. Based on cancer patients' writings, I suggest that this unwelcomed silence from the physicians' side should be replaced by a healing drama that contains narration and integrates an individual's life experience. From the ethnomedical perspective such change would also promote better results in the field of biomedicine.

## **Towards modern healthcare institutions**

In Finland the change to centralised healthcare institutions began in the 1950s. Before this change patients in need of medical help could turn to community doctors, who typically took care of whole families from newborn babies to grandmothers. Community doctors, who worked for several decades in the same place, were aware of their patients' living conditions as well as their qualities as an individual. Although patient numbers were high and doctors were expected to work with little rest, in writing collected from physicians, biographies, etc., work as a community doctor has been described as rewarding (see for example Pesonen 1990, Kantele 2006, Pasternack et al. 2006). Physicians' reminiscences point out that respect for the community doctor was high. Because of their ability to help, doctors were often regarded as superior people and thus their opinion was significant to patients. The traditional way to think about physicians as superior beings is often described in cancer patients' writing:

*Niihin aikoihin [1950-luvulla] suhtautuminen lääkäreihinkin, ja heidän suhtautumisensa potilaisiin oli kovin eri laista kuin nykyisin. Lääkäreitä kunnioitettiin tavattomasti, jopa pelättiin. Ei heidän tarvinnut antaa tietoja potilaalle. Viittaa isäni tapaukseen [1950-luvun alussa]. Hänhän sai tietää vasta leikkauksen jälkeen syövästään. On myös otettava huomioon, että niinä aikoina "otettiin vastaan, mitä annettiin", eli: oli opittu mukautumaan vastoin käymisiin.*

In those times [the 1950s] attitudes towards doctors, and their attitudes towards patients, were very different from today. Doctors were respected, even feared. They did not have to share their information with patients. I refer to my father's case [the beginning of the 1950s]. He received the knowledge about his cancer after the surgery was done. One has to have in mind that at that time people 'accepted what was given', meaning: people were used to all kind of challenges. (205)

This kind of inequality meant also that many doctors handled their patients as totally ignorant. The book *Lääkärintyön muistoja. Läkär-*

*minnen* (Reminiscences of the Physician's Work, 2006) containing the reminiscences of Finnish physicians, includes an interesting description of medical training in the 1950s. The writer recalls her professor's words regarding people who come to visit the doctor. According to the professor, patients may be divided into two groups: a) the uneducated, who do not understand anything about these things; and b) the educated, who understand equally little (Paljakka 2006, 47). Instructions given in the book suggest that patients should obey doctors' decisions without asking any further questions, which means giving up individual control.

Comparisons between the doctors' reminiscences and patients' writing from the time before centralised healthcare institutions were established, demonstrate that doctors alone bore responsibility for the treatments given and their final outcomes. Although the available resources and the work conditions were poor, people who came with their health concerns to doctors were in confident hands. In contrast to today, the trust shown in a doctor's skill and 'superior' position was acceptable for most of the patients because the doctor was (in most cases) familiar with his or her patients as individuals.

As the new centralised healthcare system gained its dominant position, the situation changed radically. The Finnish community doctor Leo Saloranta has argued that the change towards the modern healthcare system caused two major errors. The first was that doctors were made state employees, instead of being independent suppliers. The second was the change of the community doctor system to centralised healthcare, meaning that, in theory, the responsibility for the patient's condition and cure belongs to the chief physician at each healthcare centre, but in reality no one cares (Saloranta 2006, 94). The implementation of centralised healthcare meant that the treatment opportunities were more advanced, as the doctors were supplied with better equipment and facilities; however, the relationship between doctors and patients became distant, and thus, patients were no longer sure if their health was in the hands of people who truly cared. Consequently, in the cancer narratives the current situation in the Finnish healthcare system is described as a period in which new technologies and complex treatments dominate over the human being, and the integration of patients as individuals has lost its significance:

*Juuri lääkäreiden taholta saatava rohkaisu on ollut kiven takana. Tai oikeammin sanottuna sitä ei ole ollut ollenkaan. Ja kuinka kipeästi sitä tarvitaan psyyken “jälleenrakennusvaiheessa”. Olen käsittänyt että vältetään väärän toivon antamista potilaalle. Jo käsitteenä “väärä toivo” on mieleton. Sitä paitsi toivottomuudessa eläminen vie lopullisesti ne voimavarat joita potilas tarvitsee selviytyäkseen joka päiväisestä elämästä. On ollut vaikeata kohdata se asenteellisuus, jolla liian helposti leimataan koko potilaskunta yhteneväiseksi ryhmäksi, ihmisiksi jotka sairastuttuaan vakavasti kokevat sairautensa ja sen tuomat ongelmat kaikki samalla tavalla. Jokaisellahan meistä on oma historiamme ja sairaudesta huolimatta olemme yksilöitä.*

The encouragement coming from doctors has been lost. Or to be correct it is non-existent. And how much people crave for it in order to ‘build up the self’. I have understood that in this way doctors try not to give any false hope to patients. Already as a concept false hope is crazy. Living in hopelessness takes the last energy a patient needs to survive daily life. It has been difficult to accept this viewpoint, which far too easily labels all patients as part of the same group, as people who experience serious illness and all its complications in the same way. Every one of us has his or her own history, and despite illness we are individuals. (195)

Physicians working in hospital concentrate on curing the illness, which in the first place can mean removing the dysfunctional part(s) from a patient’s body using surgical routines. Chemical therapies are implemented to stop the spread of mutant cells. Thus, in cancer clinics, cancer is handled as a non-human and independent phenomenon. In this sense, for physicians the ‘medical body’ in their explanatory model is no longer the diseased patient, but the mutant cells or tissue (Helman 2000, 27). According to Lauri Honko, the conventional medical paradigm has gone through a two-step alienation of the human being. Firstly, the biological approach requires the excision of illness, usually necessitating the illness to be treated without the inclusion of the person in the treatment process. Secondly, where there is a need to include the person, the patient may be treated as a disease carrier, a non-human separated from their social context (Honko 1983, 36). Consequently, the treatments offered mean that patients, with their individual feelings, needs and lived experiences, are left without attention.

## Passive and patient

Because of cancer's biologically unique nature the period of being a cancer patient may be delineated only by the time of surgery spent in hospital. Then again, for others the pathological drama signifies an extended period filled with physical and psychological suffering taking place partly at home and partly in different healthcare institutions. Consequently, the period of the pathological drama, and of being officially recognised as a cancer patient, are for many reasons puzzling concepts. The official declaration of a cure for a patient's cancer may take up to five and in some cases even ten years. In order to make the distinction between the pathological drama and the healing drama discussed on following pages, I emphasise the change in culture-bound thinking about the individual's responsibilities as they relate to an individual's health as the illness attacks.

In everyday life people are encouraged to take care of their bodies. As I demonstrated in the fifth chapter people are rather well aware of all kinds of preventative suggestions made by health authorities, although following these is for many reasons complicated (Eriksson-Backa 2003, 175–181). When illness attacks, the cultural agreement of an individual being responsible for his or her health breaks down and poor health becomes the problem of society. To their surprise, people notice that they are no longer in charge of their bodies and what happens to them. Being involved in a pathological drama as patient means that people working in healthcare institutions gain control over a person's body and start to make significant decisions concerning their life. This kind of situation, in which individual decision making has only a secondary (not to say irrelevant) role, makes people feel uncertain and confused, particularly as the new situation is one of contradiction of the generally understood cultural agreement. In this way patients' feelings about their time spent in hospital is an interesting subject for observation.

In his article on patients' competence *Sairaan asiantuntijuus* (The Competence of the Sick Person, 2003), Finnish sociologist Ilka Kangas concluded that, compared to diabetes, allergy and depression, cancer patients are less active when it comes to their treatments, and indeed the whole pathological drama. She suggests that cancer patients are less interested in their treatments and they often leave the decision making to doctors and medical staff (Kangas 2003, 86–87). To reach

his conclusions Kangas used 21 cancer narratives from the same text corpus that is under observation in the current work. According to my expertise, Kangas' statement regarding the passiveness of cancer patients is misleading and needs to be corrected for this context.

In fact, in their writing cancer patients negotiate and propose many aspects of their treatment that they feel should have been taken into consideration or done differently in the hospital, as well as throughout their pathological dramas. Bringing out faults and mistakes that have occurred in hospital is part of the responsiveness characteristic to ethnographical writing. Respondents share their wish to be heard and noticed by medical staff. It appears that in the hospital, and during the healing drama, cancer patients are actually left without any personal opinion or the possibility to give feedback actively. Indeed, the biomedical treatments given to cancer patients are compared to other common long-term illnesses that are considered beyond everyday understanding. This however does not mean that people stop thinking about what is the best way for them to become well. If they did, the outcome would not be beneficial to anyone. Therefore, regarding cancer patients' actives, or to be precise, their inner desire to be involved in the healing drama, in reality every individual is interested in his or her health condition (see also Hawkins 1999, 129–130). Awareness of personal health is also supported by society, although unfortunately cancer patients treated in cancer clinics are in general given no choice other than to be passive and patient.

## **Patients' experiences in healthcare institutions**

The time spent in the hospital may be experienced and interpreted in multiple ways like all other events that gain significance in human life. In cancer narratives patients' feelings generally have a retrospective character, which means that the primary sensations and significant events are evaluated as being past events. I emphasise that respondents attempt to discuss the time spent in hospital and their role as cancer patients is foremost influenced by the question posed by the organisers of the writing competition: Explain how people at the hospital acted towards you as a person and a patient? Did you feel safe and did you get enough support and information? Being encouraged by this question people eagerly shared their concerns and feelings on this topic.

Patients' past experiences influence the frank descriptions given in the written narratives. In some, hospital is described as a safe place where everybody is "wounded" in some way and people at least hypothetically do not judge others according to social and cultural expectations (057, 142, 391). Other people in the same situation suffer from the lack of sympathy, support, and understanding (048, 120, 158, 164, 203, 222, 223, 257, 298, 330, etc.). The reasons for this lie in cancer's culture-bound image and the physical suffering it causes:

*Ehkä syöpä on sen kokeneelle niin pelottava asia, että mieli on koko ajan äärimmäisen herkkätuntoinen kaikelle kohtelulle. Potilaana on lisäksi niin hoitohenkilökunnan armoilla, että oma persoona ja sen rationaalinen minä tahtoo helposti olla kadoksissa.*

Perhaps cancer is so terrifying a thing that it makes you extremely sensitive to everything. As a patient you are so dependent on hospital personal that your own personality and its rational self get easily lost. (331)

According to cancer patients' descriptions, entering hospital could be described as experiencing the self placed in an unnatural environment full of challenges. The contradiction between the everyday or 'natural' surroundings of human life and the situation within the clinic may be described as denying access to natural surroundings. In everyday life people are able to enjoy the weather, trees, seasonal change, etc., whereas in hospital, where the pathological drama is handled, patients may observe nature and life outside only through the windows. This feeling is similar even if patients visit hospital for a short period or even for a few hours. The difference between 'normal life' and the abnormal situation patients find themselves in may come from simple restrictions, for example on driving a car, often seen as a symbol of freedom (289). Indeed, the hospital walls restrict patients' freedom and in this way, and not only symbolically, patients are kept apart from the 'normal' world and 'normal' people.

Entering hospital also means that people must go through certain rituals before they are accepted as patients. In Finland people are forced to give up their personal clothes and other belongings, and must put on hospital garments after entering the hospital doors. In this context removing personal clothes signifies a symbolic act that takes identity away from individuals:

*Kaunis, aurinkoinen helmikuun päivä. Pakkasta 15 astetta. Puut kauniin auerteisia ja oksissa kimaltelivat lumihuutaleet. Kaunista ja valoisaa. Oma mieleni ei ollut valoisa. Katselin maailmaa sairaalan*

*viidennen kerroksen ikkunasta. Tulin kylpyosaston kautta, kuten sairaalaan yleensä tullaan. Siellä ihmiseltä riisutaan henkilökohtainen minuus. Olen potilas se ja se.*

February, a beautiful sunny day. 15 degrees below. Trees covered with beautiful frost and in the branches snowflakes shine. Beautiful and bright. My own mind was not bright. I looked at the world through a window on the fifth floor of the hospital. I entered through the bath department, as it is usually done. There they 'unveil' the personal ego. I am a patient this and that. (158)

*Tuo lääkäri ei katsonut tarpeelliseksi minulle kertoa asiasta sen enempiä – pyysi odottamaan käytävällä. Jonkun ajan kuluttua hoitaja toi minulle muovipussin, jonne täytyi laittaa omat vaatteet. Ihmisarvoni tuntui alentuvan olemattomiin.*

That doctor did not think it was necessary to tell me more – he asked me to wait in the lobby. After some time a nurse brought me a plastic bag where I had to put my clothes. My human value seemed to disappear entirely. (360)

Hospital represents a place where people get help and support from professionals as well as understanding from others in similar circumstances (057, 142, 158). In hospital people make friends with other patients and learn to support and help each other, build up a small society or a temporary community of suffering. Therefore in some cancer narratives the period spent in hospital reminds people of good team spirit: laughing, crying and making the first steps together in order to become well again:

*Leikkauksen jälkeisenä päivänä alkoi kova kuntoutus. Olimme päättäneet kohtalotoverini kanssa, että tästä selvitään. Heti kun sai lähteä liikkeelle, lähdimme kävelylle sairaalan käytäville. Hyvin sitä jaksoi olla jalkeilla. Mietin, ettei tähän varmaan heti kuole, kun en tunne itseäni yhtään sairaaksi.*

The day after the surgery our fitness training began. With my friend in destiny I had decided that we shall survive. Immediately we could move we made a walk in the hospital corridors. We had enough energy to stand on our feet. I thought that I am not going to die of it immediately, as I did not feel myself sick at all. (142)

The social contacts or relationships made in hospital are important, and according to cancer narratives last for the rest of the patients' lives. Fellow patients may even occur in dreams:

*R. – potilastoveri, häneen olin tutustunut sairaalassa soitti kerran ja kertoi nähneensä merkittävän unen. Olimme olleet isossa porukassa siis paljon ihmisiä, nähtävästi meitä syöpäsairaita, niin hän asian selitti. Olimme saaneet lähtiessä muistoksi pienet kirjat, hänelle oli annettu kirja, jossa oli teksti “Viimeinen portti!” Minä sain kirjan, jossa luki “Jatko aika”. Tästä tapauksesta on jo yli kolme vuotta. R:n sairaus uusi aivan yllättäen – hoidoista huolimatta sairaus voitti ja hän menehtyi noin vuoden sairastettuaan! R:n sairaus kosketti minua kovasti, se oli raskas vuosi nähdä ystävän kärsivän enkä voi auttaa! Tulee usein mieleen ne keskustelut joita kävimme hänen kanssaan, hän sanoi unen käyvän todeksi, koska hän tunsu voimansa vähenevän ja lähestyvänsä “viimeistä porttia!” Minulle hän sanoi “käytä tämä jatko aika mahdollisemman täyspainoisesti, hoida itseäsi, anna aikaa itsellesi!” R:lle portti aukesi rauhallisesti hänen nukkuessaan!? Tällaista lähtöä toivoisin minäkin. Sitten kun minun “jatko aika” päättyy.*

R – the fellow patient I had come to know in the hospital called me to say she had had a significant dream. We were in a big group, apparently all cancer patients, as she explained it. We had received little books as souvenirs, whereas she had a book containing a text: “the final gate!” I got a book in which was written “continuation-time”. This happened three years ago. R’s illness returned suddenly – despite treatments the illness won and she died in a year! R’s dream moved me a lot, this was a hard year to see a friend suffering without any chance of helping! I often remember the discussions we had, she said her dream will come true, because she was losing strength and approaching the “final gate!” To me she said “use this continuation time in a balanced way, give time to yourself!” R’s gate opened as she was asleep! This kind of departure I wish for myself as well, when my “continuation time” is over. (240)

On the other hand, patient relationships in hospital can be also an intensive period of communicating and sharing, without the expectation of seeing these people in the future. Such a situation may be very fruitful for making anonymous, but very intense, connections.

When it comes to the patient-doctor relationship, one has to bear in mind that communication in hospital happens according to hospital rules, which makes individual values and personal qualities less significant (Goffman 1961, 22). To feel good in hospital people must learn to act and behave according to hospital rules. Even more, they also have to learn hospital language in order to know what is going on. Despite the potential support and help it is challenging to accept the patient’s role in hospital. According to cancer narratives, being in hospital is like being in unknown territory. Instead of feeling safe,

people feel themselves to be like a lost tourist “without a phrase book”. The metaphoric expression ‘feeling like a tourist’ may be interpreted as an uncertainty experienced in connection with entering the new social setting:

*Olo on kuin olisi oppinut kokonaan uuden kielen. Karsinoomat, biopsiat, metastaasit, ablaatiot, endokrinologiset, ym. kuuluvat lääkäreiden mielellään käyttämiin sanoihin. Aluksi tunsin itseni sairaalassa turistiksi, joka on vieraassa maassa yksyksissä ilman sanakirjaa!*

I feel like I have learned a whole new language. Carcinomas, biopsies, metastasis, ablations, endocrinologist, etc., belong to the vocabulary often used by doctors. At the beginning I felt myself like a tourist in the hospital, lost in a foreign country without a phrase book! (257)

*Minäkin opin hienoja sairaala termejä käyttämään ja tiesinkin veren kuvat ja muut muutokset, mutta tavalliselle ihmiselle ne ovat vaikean selkosia, pitäisi kysyä miten te jaksatte, miten voisin auttaa.*

I learned fancy hospital terms and I knew everything about blood pictures and other changes, but for ordinary people these are difficult to understand; instead people should be asked how they are doing, and how they could be helped. (011)

Initially, patients feel particularly insecure because they are not familiar with the hospital’s rules of behaviour and do not understand the language in use. The idea of being like a tourist shows patients’ ambiguity towards biomedical treatments, physicians’ competence and the outcome of the treatments given. Furthermore, people are also often confused by the occurrence of cancer. Thus, as one respondent explains, cancer treatments feel like *taistelua näkymättömällä näkymätöntä vastaan*, “a fight with invisible [methods] against the invisible” (352). This thought is connected to the fact that in the biomedical sense cancer has no shape or form, at least in its early stages. As people cannot see or feel cancer in their bodies, the treatments seem unnecessary and even absurd. The latter feeling is highlighted by the fact that people feel sick *after* the treatments are given (see for example 549, 555).

As time passes people become accustomed to medical terminology and the daily routines of the hospital. As this happens the rules of the clinic become clearer, and the hospital milieu begins to offer a certain safety, support, and even protection from the everyday expectations which, particularly those who do not suffer from cancer, could have towards those who do. Being in hospital offers protection from daily

challenges, because as one respondent points out, those without cancer often lack the energy and will to understand the sufferer's situation (196). Being directed by hospital routines, a patient's sense of reality becomes separated from their everyday life. Daily procedures direct the flow of time, where visits from relatives and friends represent the highlights of patients' days:

*Kohokohtia sairaalassa ollessa olivat ne hetket, kun joku kaveri tai sukulaiset tulivat katsomaan. Tuntui kummalliselta kuulla kaverin suusta selityksenä, kun ei ole käynyt katsomassa, että on kiire. Minulle sellainen asia oli niin kaukainen, minulla ei ollut kiirettä enää minnekään. Minulla ei ollut muuta kuin aikaa.*

The highlights of the time I spent in hospital were when some friend or relatives came to visit me. It felt odd to hear explanations like not having time to visit me from a friend, when they were in a hurry. For me this kind of thing felt so far away, I had no hurry anymore anywhere. I had nothing but time. (139)

In their writings several respondents point out that the loss of self in hospital is unbearable. Even if people get used to hospital rules and routines it does not mean that they would feel entirely happy in this situation. The protective walls of the social context of familiar everyday life are taken down, while patients are handled as medical bodies and thus often feel *riisuttu* (unveiled) as individuals. Far too often being a patient also means being *julkinen asiakirja* (an open record), whose concerns and treatment complications may be shared in public:

*Intimiteetin menettäminen sairaalassa on järkyttävää. Samalla kun vaihtaa sairaalan vaatteet yllään tulee julkiseksi asiakirjaksi. Potilaan sairautta käsitellään vuoteen vierellä muiden potilaiden kuulleen. Vuoteenvierusraportoinnista voi kyllä kieltäytyä. Kuitenkin käytännössä potilas näkee lääkäreitä vain kierroksella. Milloin potilas kysyy lääkäriltä sairaudestaan, jos ei kierroksen aikana? Muiden potilaiden sairaskertomukset masentavat yhtä paljon kuin oma läpikäyminen. Miksi sairastamisen pitää olla julkista sairaalassa?*

Loosing privacy is terrible in hospital. At the same time you put on hospital clothes you become an open record. A patient's illness is handled near his or her bed while other patients are listening. You can of course disagree with such near bed reports, however, in reality patients see doctors only during the rounds. When should the patient ask about his or her illness if not at the time of the round? The illness stories of other patients are as depressing as my own suffering. Why must being ill be public in hospital? (120)

*Lääkäreiden kierrot olivat välillä hyvin ärsyttäviä, sillä usein hoitohenkilökuntaa oli sängyn ympärillä hyvinkin monta. Siinä tunsin itsensä apinaksi, jota tullaan tuijottamaan. Kerrankin olin ollut suihkussa ja istuin alasti vessan pöntöllä, kun lääkärin kierto oli. Vessan ovi vain avattiin ja siinä olin alasti kaikkien tuijotettavana. En jaksanut edes suuttua. Alistuin kaikkeen. [---] Potilaana sain nähdä, miten todella ihmisarvoa alentavalla tavalla potilaisiin suhtauduttiin. Ihminen ei voi enää kovin sairaana puolustaa itseään, joten hänet lähes esineellistetään ja kohdellaan kuin esinettä, jolla ei ole tunteita.*

Doctors' visits were sometimes really annoying as there were lots of people gathered around my bed. I felt myself to be an ape at whom people come to stare. Once I was taking a shower and sat naked on the toilet seat as the doctors came. The door was opened just like that and there I was naked ready for everybody to stare. I even did not have the strength to become mad. I just gave up. [---] When I was a patient I could see, how patients were put down as humans in a humiliating way. While feeling really sick people cannot protect themselves, so they are almost turned into items without feeling. (223)

Cancer narratives point out that clinics offer little space for patients to be emotional or deal with personal needs. People going through physical alteration face psychological challenges and would therefore definitely need some privacy to gather their thoughts and rebuild themselves. However, the space for private needs is not available and this gives people a feeling that they are handled as non-humans or items. Potential support from outside is reduced to a minimum because it is not possible to discuss your problems without other patients listening. The same is true of sharing the words of support and love, not to mention sharing physical contact. The lack of privacy causes inconvenience and feelings of shame:

*Sairaalan osastolla olivat paikat täynnä. Usein käytäväpaikatkin olivat käytössä. Opin kaipaamaan yksityisyyttä. Opin sitä myös arvostamaan. Sen toteuttaminen ei ole helppoa, aina ei edes mahdollista. Kierolla osastolla käsitteellään asiiasi kaikkien kuullen, haluaisit sitä tai et. Lääkärin ja hoitajien haastattelut tapahtuivat myös potilashuoneissa, joissa on toinen potilas, ehkä useampiakin. Kuulen asioita, joita en välttämättä haluaisi kuulla, joiden tietäminen ei ole minulle tarpeen. Toinen potilas kuulee minua koskevia. Joskus mietin, olinko itse ollut kyllin hienotunteinen ja lähtenyt pois potilashuoneesta hoitoverini haastattelun ajaksi. Aina sellainen ei ole edes mahdollista.*

All the places in the hospital were full. Even the corridors were in use. I learned to miss my privacy. I learned also to appreciate it. To make it

true is not always easy, not even possible. As the physicians make their rounds your case will be handled in front of others, either you want it or not. The interviews between doctors and patients also take place in the hospital room where other patients are, sometimes even more people. I hear things that I do not necessarily want to know, that I do not have to know. Other patients hear about me. I have been thinking if I have been tactful enough to leave the room while the other is questioned, sometimes this is not even possible. (330)

In a similar manner clinical procedures also cause inconvenience and embarrassment. People have to accept their altered bodily condition: weakness, pain, lack of appetite, nausea and numerous other complications or side effects that are directly connected with biomedical treatments. The reason is the same – the individual with her or his inner feelings and needs is being excluded from the healing drama (164, 201, 203, 278, 360, 378, 390, 397, etc.). This means that cancer treatments given in hospitals leave profound imprints on the human body and on the self.

### **Physical change and its importance to the patient while in hospital**

The sociologist Arthur W. Frank, with the embodied human experience in mind, has suggested that cancer clinics may be defined as institutions or places in which the body gains new significance, giving new meanings to the self (Frank 1991, 49). The physical experience, which is very significant to cancer patients' everyday lives, takes on a different value in written narratives – it becomes a fixed interpretation of individual feelings that must gain certain structure, to be understood by others. Because of its ethnographic nature, cancer patients' writing highlights above all the cultural dimension of the discourse. In this discourse the embodied experiences gained in the hospital are represented only as a metadimension belonging to the cancer experience. By which I mean that the 'cuts' to the body and other similar memories are gained in the hospital, but that their importance grows as people are confronted with the normal setting of everyday life, including cultural expectations towards one's body.

For example, losing hair is a terrible thing from the cultural point of view as shaved heads traditionally symbolise radically marginalised positions in society (Bromberger 2007, 394). Cancer patients are cultur-

ally taken to be in the marginal position anyway, and if they lose their hair, the stigma becomes visibly detectable. From the biological and medical point of view, hair loss is not an issue, but from the cultural and personal perspective it may be very important. Therefore it should be taken into consideration when dealing with such issues:

*Kun tästä tukan lähdestä puhuin yhdelle hoitajalle hän väheksyi huoltani sanoen, että eihän kalju ole miehelle mikään paha asia. Minulle se oli erittäin arka asia kaiken muun lisäksi. Hoitajan mielestä syöpäpotilas saa näyttää miltä vaan. Pääasia on, että häntä hoidetaan.*

As I mentioned losing hair to one nurse, she told me that being bald is not so bad for a man. For me it was a really bad thing in addition to everything else. Nurses think that a cancer patient may look like whatever. The main thing is that he gets his treatment. (278)

*Solomyrkyt aiheuttivat myös sen, että minulta lähti hiukset. Oli kama-la tunne aamulla, kun katsoi tyynyä, joka oli peittyneenä irronneisiin hiuksiin. Häpesin valtavasti kaljua päätäni. Keväällä hävetti kulkea pipo päässä, kun muut olivat avopäin.*

Because of cytostatic treatments I also lost my hair. It was a terrible feeling in the morning when I looked at my pillow covered with hair. I was ashamed by my bald head. In the spring I was ashamed to walk with a cap on as others were without. (139)

Patients' memories about their bodies, described in my materials, have to be seen as to some extent different from their everyday experiences. The body memories, such as loss of a breast, or even both, or loss of reproductive organs or hair, derive from the hospital setting but are not necessarily first in the line of patients' reminiscences gained in healthcare centres. The written texts indicate that to cope with the illness and changed body image, the 'sense experiences' gained during the healing drama in the cancer clinics are essential:

*Tuli aika katsoa peiliin. En huutanut, pyörtynyt. Näin teipillä peitetyn pitkän haavan. Rintaa ei ollut. Asian hyväksymisessä vammaisuuteni auttoi. Minulla ei ole mannekiinin vartaloa. Kotiinlähtöä edeltävänä yönä valvoin. Sairaalassa ollessa on "turvassa". Sieltä löytyy aina joku, jolle voi puhua sairaudestaan ja pahasta mielestään. Ystävillekin kyllä, mutta ei aina. Sairaalassa on myös "puolueettomalla" maaperällä, kaukana ympyröistä, jossa tämä asia on hyväksyttävä ja opittava sen kanssa elämään.*

The time came to look at myself in the mirror. I did not scream, did not faint. I saw a long wound covered with tape. No breast. The fact that I was disabled [childhood tuberculosis] help me to cope. I have not the

body of a model. The night before going home I could not sleep. In the hospital you are 'in safety'. There you always find someone to whom you may talk about your illness and upset mind. With friends as well, but not always. In the hospital you are also on neutral ground, far away from the surroundings in which this thing must be accepted and coped with in order to live with it. (158)

As I have demonstrated above, many respondents wish that doctors and other medical personnel would notice and approach them as individuals. This however seems impossible, as the situation is one in which contact between patient and doctor is reduced to a minimum. The changed body condition and its cultural and personal significance, as well as patients' other feelings about the self, are often interpreted as insignificant within the medical paradigm as long as the patient stays alive. Modern doctors working in centralised hospitals are seldom familiar with their patients, which means that in practice doctors only deal with the biomedical challenge. As part of their duty of care, doctors aim to repair, remove or replace dysfunctions at the biochemical, cellular and even molecular levels. In my opinion justifiably, patients find it objectionable to be reduced to a set of biological functions in this way. Cancer patients prefer to be approached as a whole person including body, soul and spirit (330). Considering the cancer patients' culturally vulnerable position and cancer's complicated nature, I wish to suggest that every cancer patient needs their doctor's full attention, including empathy and psychological support.

### **Silent doctors**

In his article about culture and illness Lauri Honko has pointed out that when illness is interpreted as a message used by patients to express their life situation, the message stays unread as the doctors concentrate only on removing the illness (Honko 1994, 17). As pointed out in chapter five, which deals with popular explanations for cancer, cancer patients often argue that falling ill with cancer is connected with their individual life course. Unfortunately, patients' individual explanatory models are almost never considered by medical practitioners; rather, Finnish doctors prefer to stay silent. One respondent even compares the relationship between the patient and doctor as equal to that between God and his earthly servants, in which the latter may

pray, but the answer never comes: *Potilan ja lääkärin suhde on kuin rukoilijan ja jumalan* (306).

Subjective and culture-bound ideas about cancer's origin differ from the rational and evidence-based explanations used by medical professionals. For cancer patients, however, cancer is not simply the territorial expansion of a mutant clone, it means much more. Cancer could be interpreted as an individual tragedy causing physical, psychological and social suffering. In this situation, patients desire a sufficient patient-doctor relationship in order to find a mutually satisfying explanation for a particular illness episode, and in order to help in their aim for holistic recovery. Unfortunately, the analysed cancer narratives reveal doctors' unwillingness to discuss the individual course of the illness with their patients: the reasons for cancer's occurrence, the meaning of the treatments given and the achievable outcome. Instead, these narratives show doctors as distant and overconfident professionals persistently short of time.

I have previously discussed the meaningful silence that surrounds cancer discourse and the silence that I sensed (existent but unwritten) when analysing the texts. It would seem noteworthy that a particular silence also has significance in the context of the healing drama as practised in healthcare institutions. The reasons for doctors staying silent and distant may be interpreted as an unfortunate lack of personal ability, or as the result of an overlooked part of medical training:

*Samoin kirurgit eivät välttämättä ole maailman parhaita lohduttajia tai tukijoita; eräs tunnusti yhdessä luentotilaisuudessa: "Me emme tunnetusti ole maailman parhaita keskustelijoita!" Minun mielestäni lääkärin tärkein ominaisuus on kuitenkin ammattitaito, mitään yliihmisen kykyjä heiltä ei pidä vaatia, mutta hiukan enemmän empaattista valistusta heidänkin taholta ehkä sopisi toivoa.*

The surgeons are not necessarily the world's best comforters or supporters; one of them admitted in one lecture: "As is well known we are not the world's best speakers!" I think that a physician's most important quality is his or her professional skills, no one should expect from them the skills of a superhuman, but perhaps a little bit of empathic enlightenment could be wished from their side as well. (147)

Additional criticism considers the lack of time as due to the lack of human resources (024, 030, 046, 048, 061, 124, 125, 150, etc.). However the meaningful silence practised by medical professionals regarding

cancer patients is also an interesting phenomenon from a cultural perspective.

Before the twentieth century the main institutions dealing with cancer were hospitals for the terminally ill (Porter 1999, 577). Because of social demand the situation changed and societies began to support cancer studies. Despite the enormous amount of funding spent every year on these studies, it has remained a misunderstood disease. Therefore, the reasons for doctors' distant behaviour and the silence described in cancer patients' writing may be linked to cancer's biologically complex nature. In biomedical terms all carcinomas arise or are initiated, and are then boosted by, gene mutations in single cells. Why such mutations take place is still under study and new ideas are proposed every year. These highly-valued explanations are incapable of offering treatments with definite outcomes. Therefore, I suggest that the silence practised in healthcare institutions may be seen as a result of a socio-historic development.

According to the biomedical paradigm, all assumptions and hypotheses must be capable of being tested and verified under objective, empirical and controlled conditions (Helman 2000, 79). Unfortunately for physicians, as well as for patients, the nature of every cancer is unique and its course unpredictable. Accordingly, the biomedical explanatory model for cancer simply lacks the requisite scientific rationality and therefore a significant cause of doctors' silence is their respect for the biomedical paradigm. As doctors cannot be scientifically rational and objective about the causes of cancer, they leave patients with no explanation, and patients do not understand it:

*Kysymys: Saitko tarpeeksi tietoa?*

*Vastaus: Ainoa (lue ja kirjoita: ainoa) pieni puute [sairaalassa] oli se, että tietoa ei tullut! Kyllä olisin monesti halunnut lääkärin suusta kuulla esim. suoritettavan kokeen tarkoituksperästä! Kuuluukohan "mykkyys" lääkärin etiikkaan? (Tuo ei nyt varmaan ollut sovelias kysymys.)*

Question: Did you get enough information?

Answer: The only (read and understand: the only) little problem [in the hospital] was that I got no information! I would have liked to hear from the doctor's mouth about the meaning of some procedures! Is being 'dumb' part of doctors' ethics? (This was perhaps not the most suitable question.). (060)

It seems that in order to protect patients from unfortunate misjudgements, doctors have adopted the idea that awareness about the

possible causes of cancer, and suggestions about the expected course of the illness, cause suffering among the patients. This kind of myth forces cancer patients to study popular medical books, read various cancer booklets and search for additional information by themselves (Siponen 2003, 154). Individual judgements, based on unreliable sources and other patients' experiences, may lead to unfortunate misinterpretations and increase suffering. For someone who is not source critical enough, the information that with his or her type of cancer the survival rate is 20% may be devastating. In the worst case such misleading information affects patient behaviour and individual decision making as it relates to personal health during the whole illness process. In such unfortunate situations, the doctor's role would be to explain that every statistical curve has a long tail, which indicates that many people continue normal life after cancer is cured (Servan-Schreiber 2008, 89–92).

The situation surrounding the silence within the medical paradigm is in fact quite similar to the popular discourse on cancer. The unique nature of cancer adds a great deal of uncertainty and pressure to any pathological drama relating to that illness. As no one knows its consequences, a patient's relationship with their doctor has a very important function in terms of feeling safe. The prospect of working in mutual understanding with physicians has a major significance for patients, who feel responsible for their own health. If doctors stay distant and silent, an individual's sense of being stigmatised only grows.

Cancer patients' writing represents a critical interface between themselves and the scientifically proven, rational, approach of modern biomedicine. Physician's chirurgical skills mean a lot to patients, but additionally they wish to be approached as individuals whose needs are integrated into the treatment process:

*Juuri lääkäreiden taholta saatava rohkaisu on ollut kiven takana. Tai oikeammin sanottuna sitä ei ole ollut ollenkaan. Ja kuinka kipeästi sitä tarvitaan psyyken "jälleenrakennusvaiheessa". Olen käsittänyt että vältetään väärän toivon antamista potilaalle. Jo käsitteenä "väärä toivo" on mieleton. Sitä paitsi toivottomuudessa eläminen vie lopullisesti ne voimavarat joita potilas tarvitsee selviytyäkseen joka päivästä elämästä. On ollut vaikeata kohdata se asenteellisuus, jolla liian helposti leimataan koko potilaskunta yhteneväiseksi ryhmäksi, ihmisiksi jotka sairastuttuaan vakavasti kokevat sairautensa ja sen tuomat ongelmat kaikki samalla tavalla. Jokaisellahan meistä on oma historiamme ja sairaudesta huolimatta olemme yksilöitä.*

The support from doctors has been concealed. Or to be correct there has been no support at all. And how much one misses it during the reconstruction of one's psychology. I have understood that they [doctors] try to avoid giving false hope to patients. The concept 'false hope' is mad. Living in hopelessness takes the rest of the energy that the patient needs to survive daily life. It has been difficult to face the attitude that stigmatises all patients to one singular group, to people who experience their illness and all problems caused by it in the same way. Every one of us has his or her life story and despite our illness we stay individuals. (195)

*Tunsin todella olevan yksin hätäni kanssa. Tuntui vaikealta palata hoitoja saamaan. Hoitoja vain annettiin, mutta itse potilas – juuri henkinen minä jäi hoitoa ja apua vaille. En kerta kaikkiaan enää olisi halunnut nähdä hoitajia enkä lääkäreitä. Ajattelin, että kyllä ne noita temppeja teknisesti osaavat. Osaavat laimennella sytostaatteja – pistellä niitä myrkkyjä meihin potilaisiin, mutta sielua he eivät pysty tai eivät halua hoitaa. [---] Ei siinä potilaille puhuta juuri mitään. Potilaille jäi sellainen tunne, että olet vain tapaus: kylkiluu, keuhko, lonkka, umpisuoli – vain numero tilastoissa. Et ole tunteva, kärsivä, kuuleva potilas. Kenelläkään ei tuntunut olevan aikaa – ei uskaltanut kysyä mitään, kaikilla oli niin kiire. Potilas on hädissänsä, peloissaan, arka – et uskalla kysyä ja jos uskallat saatat saada hyvin ylimielisen vastauksen. Sain mielestäni hyvää sekä huonoa kohtelua sairaalassa. [---] Olen usein ajatellut sellaisia potilastovereita, jotka hiljaa alistuen tyytyvät osaansa – esim. vanhukset tai muuten arat potilaat. Miten heidän käy? Jävätkö he hoitoa vaille?*

I felt I was alone with my trouble. It felt difficult to return to be treated. Treatments were given, but the patient – particularly the spiritual self – was missing some cure and help. I just did not want to see any nurses or doctors. I thought that they know well all the technical tricks. They can mix the cryostats and put this poison into us, patients, but our souls they cannot or do not want to heal. [---] To patients they say almost nothing. Patients get the feeling of being a case: rib, lungs, hip, or appendix – only a number in the statistics. You are not a patient who feels, suffers and listens. No one seemed to have time – I did not dare to ask, everybody seemed to be in such a hurry. The patient suffers, afraid, shy – does not dare to ask and when you do you might get an arrogant answer. I think I got both good and bad treatment in the hospital. [---] I have been thinking about this kind of cooperative patient, who shyly accepts their part – for example, old people or otherwise shy patients. How do they manage? Are they mistreated? (451)

Those patients who have experienced the desired patient-doctor relationship, describe the time spent in the healthcare centre and the treatments received as more rewarding than those who have been handled as diseased bodies. Thus, despite continuously increasing numbers of patients (cancer rates are increasing, partly thanks to facilities for early diagnosis) and enormous work pressure (also psychologically) doctors should still not forget that their patients are human beings, not only because of professional ethics but also because of better treatment outcomes. It could be claimed that the humanistic aspect of patient care is left to the nurses. Among their duties are both the “dirty work” as well as offering spiritual care (Widding Isaksen & Dahle 2000, 226–227). Still as doctors make decisions that concern the individual’s health, their empathy and time to talk is most valuable for patients as they have an urgent need for patient-doctor communication, and also a need to possibly negotiate individual aspects of their illnesses.

### **The power of ‘healing narratives’**

The material at hand, dealing with patients’ individual struggles with accepting the altered self in the context of treatments given in hospitals, makes me wonder how far can a human being go in accepting these alterations without losing hope, and more importantly, without losing the self entirely? In the case of cancer, the devastation and feeling of being stigmatised certainly relates not only to an individual’s body. The cultural stigma makes cancer patients feel equally insecure about their past behaviour and life. People with the cancer diagnosis often find themselves in a hopeless situation, without the opportunity of ever being ‘normal’ again. How is it possible to come out of this situation in order to regain the self?

Cheryl Mattingly suggests that patients suffering under the limitations of biomedical treatments have at their disposal a good tool with which to escape this misery. When faced with uncertainty and suffering, a common reaction is to tell a story. Mattingly proposes that “even when the pain is beyond words, when no story can be adequately told about it, a person may find that they draw upon narrative to remember and recreate a self, reaching backwards and forwards in time in search of possible worlds, possible lives” (Mattingly 2004, 73). As a matter of fact, under such conditions any singular event may become significant

for a patient's recovery, while the experience that is indeed preserved in memory can be returned to, recalled, even reheard and re-felt.

Experience, when it emerges as a unique memory-making event, bears an ambiguous quality. It has some of the qualities of an object, inscribed in memory as a particular something that can be re-presented (Mattingly & Lawlor 2001, 33). Cancer patients' writing proves that stories told, lived, and performed in hospital sustain a remarkable healing power:

*Munuaissyöpäleikkauksessa haava ulottuu melkein selkärangasta lähelle napaa – aika pitkä poikittaishaava tuosta vyötärön yli. Ja sitten, kun olin kertonut aamusella, kun pojan joukko soitti J:sta, että minulla on nyt tämmöinen haava mahassa, niin poika sanoi sieltä, että “Äiti, nyt sinulle tulee ammatinvaihto: Sirkus Finlandiassa on sahatun naisen paikka auki”. Sen jälkeen olikin niin hankala olla, että oli siinä ja siinä ettei haava revennyt, kun nauratti niin kauheasti.*

The wound after kidney cancer surgery reached almost from backbone to navel – a quite long wound across the waist. And then in the morning, when I said to my son in J., that I now have this kind of wound in my stomach, my son said: “mother, now you must change your profession. In Circus Finlandia there is a place free for sawn women”. After that I laughed so much that I was lucky the wound did not open again. (072)

*Nyt minulla oli kuitenkin peruukki ja vedin sen päähäni, ennen kuin aviomies saapui. Mies tuli ja jäi ovelle katselemaan minua. Koetin tiirailla häntä, miksi ei tule huoneeseen, vaikka tunsin hänen hahmonsä ovella ja käytävällä jo kuulin hänen puhuvan hoitajan kanssa. “Mikä sinulla nyt päässäsi on?” mies kysyy ihmetystä äänessään. “Uusi peruukki, itsehän tämän valikoit.” “Ei se tuommoinen ollut.” Otin peruukin päästäni ja sormeilin sitä. Mies tulee ja ottaa sen minulta ja nauraa sitten makeasti: “Tämä oli sulla äsken väärinpäin päässäsi.”*

Now I had the wig, and I put it on before my husband came. My husband came and stopped on the doorstep to look at me. I tried to look at him to see why he does not come in, although I sensed him being outside the door, and I had heard him talking with a nurse. “What exactly are you wearing on your head?” my husband asked with a surprised sound in his voice. “New wig, you chose it for me.” “It did not look like that.” I took the wig and let it through my fingers. My husband came and took it from me and then sweetly laughing told me: “You had it on the wrong way around.” (434)

In the hospital setting the act of storytelling has several meanings. Narrative is a reliable tool for exposing individual qualities. People may choose what they want to say and how they do it when introducing the self into the new surrounding. This is beneficial in order to become a member of the temporary community of sufferers. On the other hand, verbalising personal suffering and loss is a significant part of the patient's inner negotiation process and is necessary in order to accept the altered self. Sharing and telling stories is an important act particularly because the performed narratives may be recalled and newly imbued with meaning while the illness process is still in motion. Even when the pathological drama is over, significant personal experiences, captured as narratives, are stored in people's minds and may be reproduced. According to cancer narratives the process of recalling the experienced events via narration may be extremely rewarding. Which is to say that, narrated experiences give new meanings to the experiences gained in hospital.

Although the support of other patients, family members and friends may help to overcome individually critical situations, it is necessary to remember that the healing event performed between doctor and patient is still the most central to the hospital drama. Cancer patients' writings indicate that those moments when a physician comes closer and acts 'almost' like a human, mean a lot for patients (079, 124, 125, 150, 435), even if the general health condition, based on rational reasoning and biological evidence, is totally unpredictable:

*Keväällä saimme osastolle oikean hymypojan, lääkäri M:n. Hän jäi usein juttelemaan potilaiden kanssa ja muistan tapauksen, kun meitä oli sattumoisin kolme urheiluhenkistä miestä. Toiset minua nuorempia hoidettavia. Möykkynen jäi hetkeksi taas hymyillen keskustelemaan. Ihmettelimme sitä, että miksi syöpä voi tulla, vaikka meistäkin jokainen urheilun avulla haluaisi pitää itsensä terveenä ja hyvässä kunnossa. Möykkynen kuunteli hymyillen tapansa mukaan ja rauhallisesti sitten louhii lausumaan. "Niin, siinä on hyvä otos ja näyttö, että urheilu on vaarallista." Hänen kanssaan ei voinut kuin olla samaa mieltä.*

In spring our department got a really merry doctor. He often stayed to have a chat with patients and I remember a case where there were three sporty men together [in the hospital room]. The others were younger than I. The doctor stopped again, smiling, to have a discussion. We were wondering how cancer may come, even if everyone of us had tried to keep themselves in good condition by practising sports. The doctor listened smiling typically to him and calmly told us: "Well, there you

have a good example of the dangers of sports.” There was no other way than to agree with him. (100)

Talking, sharing and storytelling have a practical quality during the healing drama. Accordingly, I suggest that performing ‘healing narratives’, interpreted as a sign of being human, is a good opportunity to establish the equality and trust desired in the doctor-patient relationship:

*Toivoisin lääkäreiltä psykologista silmää ja joustavuutta. En pidä vähätellä parantajan persoonan vaikutusta. Usein on niin, että lääkärin sanat saavat suhteetonta painoarvoa. Sitä kummastelee että tuo tietää kuolenko pian ja hänen vallassaan ovat hoidot, jotka siitä vielä pelastaisivat. Usko siihen että tehdään yhteistyötä ja selvitään voisi merkitä paljon.*

I wish doctors had would have an eye for psychology and some flexibility. The healers personality should not be underestimated. Often doctors’ words gain too much value. Then you must wonder if this one knows that I am going to die soon and in his hands are also the cures that could still save me. The belief that we cooperate and survive could mean a lot. (453)

From the ethnomedical perspective the primary arrangement for performing a successful healing ritual is if patients and doctors find themselves in an equal position or level. Foremost, this means reducing the cultural difference between physician and patient (Honko 1994, 37). Reduced inequality is very important in order to create the therapeutic relationship with the patient. This means that patients may trust and relay their health condition and individual concerns to the doctor without hesitation. And thus, both participants, patient and doctor, are actively involved in the healing drama.

Beyond all restrictions set by cancer’s biomedical paradigm, doctor and patient have to communicate in order to search for satisfactory solutions. This kind of communication has to engage with a patient’s personal feelings, show a true interest in a patients’ personality, life story, and primary fears and concerns. This is the proper way to create ‘healing narratives’, which are performed during the time spent in hospital, and which also offer patients a valuable tool with which to replay their feelings, and also to give new value to future reminiscences.

## Conclusions

The way society deals with illness has an essential effect on the well-being of patients. If we look at the ecological history of illness, it can be approached as a certain kind of interaction between nature and human kind. If environmental conditions change, the overall picture of disease also changes (Kjærgaard 2000, 15). Some centuries ago leprosy, plague, malaria, tuberculosis and syphilis took thousands of lives in Europe daily. As these diseases lost their significance, they were listed in medical history as a victory for medicine. However, the ecological and social history of illnesses offers a different set of explanations about the change in picture of diseases during the past centuries. For example, the defeat of malaria in Nordic countries is not explainable as a medical victory. Endemic malaria disappeared almost without any preventative techniques being adopted. The newest biological studies suggest that the decline of northern malaria was connected with changes in social structure: farm houses were built differently and people no longer lived in extended families, which reduced the possibility of being infected (Huldén, Huldén, & Heliövaara 2005, 1–13). In the middle of the 20<sup>th</sup> century (at least for a short period) it seemed that biomedicine might be capable of handling all illnesses that cause suffering to humans. This illusion has vanished as AIDS, cancer, diabetes, multiple sclerosis, new forms of tuberculosis and malaria, and many other long-term illnesses make people suffer and die every day. Some of these illnesses are the results of ecological change, others can be connected with lifestyle: eating and drinking habits, physical exercise, work conditions and general wellbeing.

Every decade has illnesses that reflect the societal and cultural settings of the time. This could be called the collective destiny of mankind (Kjærgaard 2000, 24). Despite new biomedical treatments and techniques, people continue to fall ill with cancer. Even if, for some individuals, the treatments ensure health, it does not help the majority of mankind. The main reason is money, or to be more accurate, the lack of it. No society can invest so much money in a healthcare system that people can be cured according to their expectations. This could also explain why cancer patients' descriptions and stories about their time spent in hospital are so critical.

At the moment there is a discussion on the social provision of screening for prostate cancer. The main discussion question is how

many people in whom cancer is discovered, could be helped, and to whom, with nothing other than temporary relief available, would a discovery cause unnecessary suffering. It has been suggested that men with cancer cells in their *prostata* could live without any complaints into old age. Whereas when cancer is discovered and treated, only one man in a thousand can be healed (Petäys 2003). The discussion surrounding Prostate Specific Antigen (PSA) tests mainly has an economic and medical dimension: specifically, how much money can be provided, who should pay and what extra efforts would be required from medical personnel? The cultural and societal dimensions seem to be insignificant.

In previous chapters I have described what it means to be diagnosed with cancer and what it means to have it from the patient's perspective. In this chapter I pointed out that for many respondents even the time spent in hospital, which is the officially approved path back to health, does not offer the expected relief in a holistic sense. The situation is rather the opposite: many cancer patients suffer from radically changed physical conditions and a lack of attention. Rather than feeling that they are being cured, they feel that they are being exposed in some way as individuals and then left alone with their feelings. From the cultural point of view, people seem to long for a more human approach particularly from their doctors, who are made responsible for the successful healing drama.

If our society has agreed on a particular path for the healing drama then this path needs a radical change, particularly in the areas of the patient as individual, and patient-doctor communication within the healthcare system. The treatments given in hospital are guided by doctors who represent the biomedical paradigm. Based on the cancer narratives I emphasise that among doctors' responsibilities should be support for cancer patients as individuals. Otherwise, patients perceive the healing drama as unsuccessful. Above all, this means that doctors should be interested in their patients as personalities. They should have not only the time, but also the interest, to listen to their patients' ideas, doubts and stories. Furthermore, physicians should have personal qualities that allow them to communicate with patients on an equal level in order to give patients the feeling of being safe and properly cared for.

# WRITTEN CANCER NARRATIVES

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

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