

## 8. Methods of Coping and Alternative or Complementary Self-Help

When patients suffer from a lack of doctor's attention in the hospital they decide to search for self-help methods to become well again. The self-help methods selected are mainly those that complement the lack of attention towards patients' personal needs and desires. Active patients who wish to improve an unsatisfactory situation understand the need for self-help in order to cope with the situation and to find a way out in terms of recovery. These active patients try to regain control of their bodies and lives, and therefore search for various self-help methods to accomplish this. The self-help that cancer patients adopt may be connected with, for example, daily food intake or physical or spiritual exercise, which in general aim to give a more controlled and balanced life.

Cancer patients who entered the writing competition do not form a homogenous group of people. In everyday life they may have very different expectations of their own wellbeing and health. Their life conditions and situations are dissimilar as well. Therefore, one should be aware that patients' abilities to cope with having cancer and to find suitable coping methods are dependent on numerous aspects. Normally the dominant expectations influencing the individual become expressed in their writings, which naturally help the interpretation process.

Above all, by adopting the role of active patient, people demonstrate their need to do/change something about their condition. This attitude is based on a very common belief, present in the cancer narratives, that if people do not help themselves, no one else can help them. This belief

matches neither the expectations of the socially approved healthcare system, nor the doctors within it who expect people to give up control as they take on the role of patient. This makes the cancer patient's decision making, about how they make use of the available domestic or alternative treatments, complicated in many ways.

In everyday practice, the dominant position of evidence-based medicine means that Finnish doctors concentrate on a patient's body and hardly ever suggest anything that does not belong to the category of conventional treatment. Studies have shown that about one or two percent of doctors recommend cures to their patients that are not biomedically approved. Even fewer doctors collaborate with other medical practitioners, such as zone therapists, chiropractors or folk healers (Hernesniemi 1991, 14–15; Hernesniemi 1994, 126–138). Public debate about the possibilities of implementing complementary and alternative treatments began at the end of the 1970s (Vaskilampi 1994, 227). These discussions were passionate and one-sided (Ryypö 2004). Looking back on that period, there was very little scientific argument about the potential of complementary and alternative healthcare, although it was evident that people made use of it (Meriläinen 1986). This also represents the current situation in the Finnish healthcare system.

In this chapter I will observe how Finnish cancer patients describe their use of complementary and alternative treatments as forms of self-help. I emphasise the cancer patients' reasoning about the use of complementary and alternative treatments in a situation dominated by conventional healthcare. Furthermore, I discuss the general meaning of debating the implementation of unconventional treatments as a path for self-help within the context of the cancer narratives. My suggestion is that the argumentation about various treatments may be interpreted as an important part of internal negotiation within narrative representations of the illness process (Lehmann 2007, 198–200). Foremost, its significance is in the prospect of regaining control of one's life. In addition to this, because of the almost underground position of complementary and alternative treatments, discussing opportunities for self-help represents a confrontation with the socially agreed conventions on cancer treatment.

## **Arguments regarding the need for self-help**

I use the concept 'self-help' to refer to all kinds of treatments and procedures that cancer patients find useful in order to feel, and become, better. Thus, a significant self-help method could be mushroom picking in the forest (033), drinking beetroot juice every morning (044), taking long walks (073) or sharing a moment of prayer with supportive friends (167). Although evidence-based medicine is seen as the dominant healthcare system in Finland, people are used to taking care of their own health, and thus primary healthcare is usually practised at home, before patients bring their concerns to the doctor's office. This could be interpreted as a part of modern health awareness, but also as culture-bound behaviour because all kinds of health concerns are initially handled at home. Such behaviour has its roots in tradition, in which domestic cures and healing practices were the most important means of becoming well.

As I have demonstrated in previous chapters, discovering cancer may be a long and complicated process, and thus the period before the diagnosis may be full of attempts to regain health using various products suggested by friends, available in grocery shops, pharmacies or specialist shops selling natural products (011, 031, 052, 059, 066, 085, 088, 102, 147, etc.). In the cancer narratives there is little about the use of traditional healing methods deriving from Finnish folk medicine for the relief of pre-symptomatic conditions. Common behaviour is for people feel who exhausted but have no other symptoms to take vitamins, minerals or natural products in order to become fit. When suffering pain they consume painkillers. If the complaint continues, people decide to visit the doctor. The pathographies used in this thesis show that the majority of Finnish patients prefer and trust conventional healthcare because it is the only healthcare system they know. Studies carried out in the 1980s and the beginning of the 1990s indicate that Finns used public healthcare services more eagerly than any other nation in the European Union (Koponen & Aromaa 2005). In contrast to the United States and some other European countries, treatment costs do not affect patients' decision making as public healthcare is state funded. On the other hand, recent studies have shown that the use of complementary and alternative treatments is rising among patients with long-term and serious illnesses, particularly as

people are not satisfied with the treatments offered by the conventional healthcare system.

Cancer narratives demonstrate that almost immediately after the diagnosis of cancer, patients start to consider the possible use of complementary treatments. The cancer narratives show that when patients are not themselves interested in alternative treatments, there will always be plenty of friends, colleagues, acquaintances, other patients or even hospital staff who suggest non-conventional cures:

*Muutamat ihmiset neuvoivat minulle – varmasti ihan vilpittömässä hyvántahtoisuudessa – keinoja tautini parantamiseksi. Useammatkin tiesivät neuvoa nauttimaan erilaisia vitamiinipillereitä. Eräs kertoi itsellään olevan tuttavän, joka oli parantunut syövästään juotuaan muutaman viikon ajan joka päivä lasillisen elintarvikeliikkeestä ostamaansa eläimen verta.*

Some people advised me – probably wishing all the best in their hearts – all kinds of cures for my disease. Several people suggested different vitamins to me. Someone told me about a friend who got rid of his cancer [leukaemia] by drinking a glass of blood every day for several weeks. (233)

*J:n voinnista kiinnostuneet tuttavat atoivat minulle kaikkia neuvoja. Kouluterveydenhoitaja oli myös tuttava naapuri. Hän neuvoi, että leukemiassa on auttanut neekerin veri, jos sitä veren siirrossa laitetaan, koska se on erillaista. Jotkut neuvoivat tuhkevettä (ymm).*

People interested in J's condition advised me of all possible cures. The local school nurse was also or neighbour. She said that Negro's blood had proved to be helpful in leukaemia if they make the blood transfer, because it is different. Others suggested birch ashes, etc. (011)

Accordingly, from the moment of diagnosis people are constantly faced with suggestions and proposals about unconventional treatments. Some patients see this as a natural part of their healing process, whereas for many patients the possibility of having another path to wellness represents a great individual challenge that is underlined by the cultural discredit usually attached to the use of alternative treatments. Despite the rising interest in alternative cures, people do not feel comfortable combining conventional medicine with complementary treatments. The cancer narratives tell us that the use of complementary and alternative treatments are taboo subjects for conventional doctors, and thus, any use of such treatments causes uncertainty and hesitation among patients:

*Mä pelkään aina, kun laitan jotain suuhuni tai kun en laita. Kirjoissa puhutaan asioista monin eri tavoin. Mä en uskalla syödä vitamiineja ja hivenaineita, vaikka uskoisinkin niiden vaikuttavan positiivisesti. Mä haluan mennä hivenainelääkärille.*

I am always afraid: either I put something in my mouth or I do not. In books they explain things in different ways. I am afraid of eating vitamins and minerals, even if I believe that they might have a positive influence. (087)

This means that patients who are not entirely satisfied with their treatment process at healthcare centre, or who want to improve their general health with the help of non-conventional methods, are often forced into situations in which they have to make use of complementary and alternative treatments in a secretive manner, thus confronting the social norm. According to cancer narratives the prospect of combining conventional and complementary treatments to improve a patient's health seems somewhat impossible to doctors (202, 230, 288, 335), although attempts to understand and find compromises would certainly be more beneficial (033, 059, 100, 205, 206, 275, 520). Some doctors even force patients to choose: either use conventional medicine or go for alternative treatments. So, patients have to make the decision alone, and unfortunately in secret, to avoid their doctor's annoyance (see also Hernesniemi 1987, 67):

*En tiedä miten muut syöpäpotilaat ovat kokeneet "sodan", jota viime vuosina on käyty virallisen- ja ns. vaihtoehtoisen hoidon välillä. Tuskin kuitenkaan olen ainoa, jonka mielestä kyseinen repivä keskustelu on vain lisännyt paineita ja epävarmuutta potilaiden keskuudessa. Osalla meistä on luullakseen hyvin hatara käsitys siitä, mitä nimenomaan vaihtoehtoinen syövänhoito pitää sisällään. Tilanne on johtanut siihen, että "normaalien" hoitojen lomassa nautitaan joku vitamiinipilleri päivässä ja kannetaan huonoa omaatuntoa moisesta lipsumisesta kielletylle alueelle. Miksi ihmeessä näistä asioista ei voida hoitoyksiköissä avoimesti keskustella potilaan kanssa!*

I do not know how other cancer patients have survived the 'war' that has been taking place between conventional and alternative medicine over the last years. I doubt I am the only one who thinks that this passionate debate has only added to the stress and uncertainty among patients. Some of us have no idea what alternative cancer treatment means. This has led to a situation that sees people take few vitamins and feel bad about sneaking to forbidden grounds. Why on earth can these aspects not be discussed openly with patients? (195)

The given example, in a similar way to others, highlights the urgent need to discuss the use of complementary and alternative therapies more openly in order to avoid the psychological pressure caused by secretive use of unconventional treatment. Some openness would have a positive result for doctors as it would help to avoid possible harm caused by combining biomedical therapies and complementary treatments. This is particularly true once patients leave hospital and become responsible for their own health once they are out of hospital. This means that theoretically people may decide on any suitable self-help method, even contradicting the doctor's prescriptions. Above all the possibility of making decisions about their own health makes people feel relaxed and satisfied:

*Päivä päivältä voin paremmin ja 13. päivänä leikkauksesta lähdin lomalle etelään mukana unitabletit ja särkypillerit. Kertaakaan en nauttinut niitä, vaan otin mieluummin lasin valkoviiniä aterialle ja huomasin, että olen iloisempi ja rentoutuneempi kuin ainaisessa "pillerihumalassa".*

Day after day I felt better, and on the 13<sup>th</sup> day after surgery I went on vacation with sleeping pills and painkillers. I did not use them, but preferred a glass of wine. I noticed that I am happier and more relaxed than when being 'poisoned by pills'. (137)

*Hemoglobiini oli leikkauksen jälkeen 108. sen katsottiin olevan normaali, mutta hain kohta kotiin päästyäni apteekista rautaa.*

My haemoglobin was 108 after the surgery. They said it was normal but as soon as I went home I bought some iron pills from the pharmacy. (140)

*Aloitin taistelun kuntoni suhteen. Join esim. jotain männynuutejuomaa 2000 mk:n edestä. tilasin sitä jostain Keski-Suomesta aina satsin ja koin mielestäni sen erittäin vahvistavaksi. Samoin tuhkalipeää join useamman vuoden ja nautin vitamiinipillereitä. En tiedä, auttoivatko em. asiat paranemiseni, mutta toivoa ne antoivat.*

I began to fight for my health. For example I drank some kind of extract made of pine-tree that cost 2000 marks. I ordered it from Mid-Finland and felt it to be really empowering. For several years I also drank birch-tree ashes in water and took some vitamins. I do not know if these things helped my recovery, but they gave hope. (542)

Thematically, cancer patients' narratives give five general reasons for choosing complementary and alternative treatments. Firstly, patients feel that conventional treatment is somewhat insufficient: *Virallinen*

*lääketiede käski minun vain odottaa pari tuntia radioaktiivisen aineen imeytymistä, maata ihan liikkumatta puolisen tuntia, tulla kuulemaan tulokset viikon päästä... Kysymyksessä oli kuitenkin minun elämäni,* “The official medical opinion was for me to wait while the radioactive substance sank in, lay without moving half an hour, come to hear the results in a week... It was after all my life” (202). The feeling of insufficiency usually begins when doctors ‘treat only cancer’ and leave the patient, as an individual, without any attention. Patients suffer physically and mentally because of their illness: *Itseensä käpertyminen ja vaikeroiminen on pahasta, kyllä fyysinen ja psyykinen olemus kulkevat käsi kädessä,* “Being an introvert and silent is bad, indeed, the physical and spiritual self go hand in hand” (056). Patients worry about their work, family lives and the wellbeing of other family members. They are concerned about their futures. They analyse the reasons for their illness. If they find that something in their past was unbalanced, they want to fix it (066, 075, 088, 184, 318, 331, etc.). As doctors concentrate only on cancer treatment, patients look for complementary cures that might help a holistic recovery.

Secondly, patients feel the urge to improve their condition in every way possible (052, 059, 085, 100, 125, 153, 322, 366, 542, etc.). They are concerned about their physical condition and think that their active participation in treatment should guarantee recovery. They study all the books about cancer they can find and analyse different materials available relating to their illness. They are ready to change their lifestyle for the better and therefore try everything that might be helpful:

*Kun vähän aloin toipua, tuli minulle valtava elämänhalu. Kyselin kailta tuttavilta syöpäpotilailta, mitä he olivat tehneet parantumisesna eteen. Luin kirjastosta kaikkea, mikä koski syövän hoitoa kotikonstein. Otin selvää ravintoasioista. Sain yksityislääkäriltäni hiven- ja vitamiini-pillerit. Kävin tutustumassa elävän ravinnon kasvattamiseen. Laitoin viher- ja punajuuri mehut. Kasvatin ituja ja versoja. Kuuteen vuoteen en syönyt lihaa. Ainoastaan kalaa- ja vihannesruokaa.*

When I recovered a little I got such an urge to live. I questioned all my fellow cancer patients about what they had done to help themselves. I read everything available from the library that dealt with the domestic care of cancer. I understood things concerning food. From a private practitioner I got some minerals and vitamins. I went to see how to grow macrobiotic food. I prepared vegetable and beetroot juice. I grew cereal germs. For six years I did not eat meat. Only fish and vegetables. (044)

Thirdly, patients feel desperation and weakness caused by conventional medicine's sometimes radical treatments. For example, chemotherapy makes patients nauseous and weak. Patients lose their appetite and lose weight, lack energy, and finally their desire to live. In this case, alternative therapies are used as first aid to get back the appetite and with it the will to continue:

*Ylilääkäri kysyi minulta oliko kipuja. Eihän niitä ollut, kun vain pääsisin pahoinvoinnista. Jospa saisin puolukkaa, niin varmaan tokenisin. Neuvoteltuaan leikannen lääkärin kanssa, määräsi ylilääkäri minulta pois kipulääkkeet, ja kehotti kokeilemalla puolukalla oloni parantamista. Myöhemmin saatiin selville, että olen yliherkkä morfiinille. Puolukalla olin aina kotona saanut pahoinvointini pois ja ruokahaluni kasvamaan. Ja siitä tuli parannuskeino nytkin.*

The senior physician asked if I had pain. I did not, but the nausea was a problem. If I could get some whortleberries I would surely get better. After having a talk with my surgeon the senior physician denied my pain-medication and told me to try with whortleberries to make myself feel better. Later I heard I was allergic to morphine. With the help of whortleberries, I have always got rid of the sick feeling and improved my appetite at home. And this was a cure in itself. (205)

*Tuli maanantai ja tuli tiistai ja akka vain oksensi. Mitään ruokaa ei enää tehnyt mielikään. T., aviomies, haki sitten kaupasta ykkösolutta eli pilsneriä ja sanoi "otappas tuota, joku sanoi sen olevan hyvää huonovointisuuteen." Join sitä ja itkin, se oli mielestäni kamalla juotavaa. Se kumminkin piristi ja ei tullut enää ulos. Voin jo vähän syödäkin, aloitin sillin palasesta. Joten oli siinä "elämän eliksiirit" suolasilli ja ykköskalja.*

Monday came and then Tuesday but this woman was only puking. Food had lost its taste. T, my husband, got some low alcohol beer from the grocery store and said "take some, someone told this helps against nausea." I drank it and cried, this was an awful drink. But it pampered me and I did not puke anymore. I could even eat something, and I started with a piece of herring. So there were my "elixirs of life" a salted herring and a beer. (268)

Fourthly, patients feel the need for change in their personal lives (009, 046, 079, 050, 098, 214, 265, etc.). Patients who have survived cancer, analyse the period of their lives before they fell ill. They look at past behaviour and want to make a new start. Anne Hunsaker Hawkins has noted that the myth of rebirth is central in many pathographies (Hawkins 1999, 33). This particular myth is also an important organising construct that concentrates on traumatic experience and personal



change. That is why many cancer patients talk about life before and after cancer. Life after cancer is experienced as a new opportunity. People experience things they only considered before, change attitudes and manners, choose new hobbies and think more about their own wellbeing.

Finally, sometimes doctors declare treatments unsuccessful, or that the cancer has developed so radically that conventional medicine is incapable of helping. For those patients complementary and alternative treatments signify the last hope. At this stage many patients have given up their desire for recovery and so complementary treatments become the concern of relatives or close friends. Relatives and friends are often encouraged by the stories of miraculous recoveries. According to cancer narratives, in some cases alternative treatment as the last hope has indeed been helpful:

*Sairaus eteni hoidosta huolimatta ja viimein marraskuun alussa vuonna -79 lääkäriini todesi hoidon tuloksettomaksi, joten ne lopetettiin. Lopullisen tuomion kuultuani eristäydyin kotiin odottamaan lopullista poislähtöä tämän maan kamaralta. [---] Luin lehdestä dosentti Tallbergin immunoterapiahoidosta ja viimeisillä voimillani päätin vielä yrittää sitä hoitomuotoa. Pääsinkin tutkimuspotilaaksi heti joulukuun lopulla -79. Lähdimme aivan nollopisteestä taistelemaan ruumiissani riehuvaa sairautta vastaan. Sain ojentautua aivan kuin hukkuva viimeiseen oljenkorteen. Hoito rupesi päivä päivältä ja viikko viikolta tuotamaan tulosta. Fyysinen olemus kuntoutui, samalla myöskin henkinen minä uudistui. Jaksoin taas uskoa huomiseen, sen mukanaan tuomiin haasteisiin! Olen niin onnellinen, että olen saanut elää noiden kahden epätoivoisen vuoden jälkeen 15 vuotta täyttä elämää.*

My illness continued to spread despite the treatments and finally, at the beginning of November '79, my doctor said that the treatments were not working, so they must stop. As I heard the final sentence I closed myself into my home to wait for the final leave from this earth. [---] I read from the newspapers about the immunotherapy given by docent Tallberg and with my last strength left I decided to try this cure as well. I got a place as a research patient at the end of December '79. We began from zero to fight against the illness demolishing my body. I was my last hope. The treatment began to function day after day, week after week. My physical self got better and at the same time my mental self was recharged. I could believe in tomorrow again and in its challenges! I am so happy that I have had a chance to live 15 full-bodied years after those two years full of desperation. (295)

This kind of narrative, about miraculous recovery with the help of alternative methods, are rather popular in everyday communication. These stories are used to assure people that alternative and complementary treatments really help, even in the most dramatic cases.

## **Complementary treatments in use**

In the following table (Figure 17) I have listed the various alternative and complementary self-help treatments mentioned in the cancer narratives. As the border between conventional and alternative medicine is constantly changing, the self-help treatments listed in the table were not, according to cancer patients, prescribed by doctors. In the narratives, the usage of vitamins and minerals is perhaps the most common alternative treatment. Today the consumption of vitamins and minerals does not belong to the category of alternative and complementary self-help, as this method has been accepted by evidence-based medicine as useful and made a part of cancer treatments. The same thing has happened to lymph therapy, which at the beginning of the 1990s was seen as an alternative method, while today it is suggested to breast cancer patients who have problems with swollen arms.

In order to capture the variety of treatments used, I have divided the cures sought into three analytical categories: biologically based practices, mind-body medicine and energy medicine. These categories ought to reflect the fact that, as with the folk medicine of the past, today people combine numerous treatments, as their main concern is to be cancer free and recover from illness.

As the alternative and complementary cures are divided to three categories, I shall discuss these in separate sections.

## **Biologically based practices**

The results indicate that all biologically based practices, such as herbs, foods, dietary supplements, vitamins, minerals and antioxidants are very popular. Their biological impact and usefulness has been thoroughly analysed in Pertti Arkko's book *Syövän kansanlääkinnän menetelmät Pohjois-Suomessa* (Folk Medical Practices for the Treatment of Cancer in North Finland, 1986). From the ethnomedical point of view the main intention of these treatments is to purify and strengthen the patient's body in order to fight the 'outside intruder'. In

<b>Biologically Based Practices</b>	<b>Mind-Body Medicine</b>	<b>Energy Medicine</b>
<b>Herbs:</b> garlic, onion, linseed oil, pine needles, parsley, cabbage & rhubarb leaves, Tibetan mushrooms, nettles, etc.	<b>Patients support groups:</b> Support person Support groups Rehab campus	<b>Bio-field therapies:</b> Therapeutic touch Reiki
<b>Foods and Dietary Supplements:</b> Fast food, vegetarian food, raw food, macrobiotic food, birch tree ash, fruits and berries, beetroot & rutabaga juice, calf's brain, fibre, cereal germs, seeds, cognac & eggs, vodka-salt-water, light beer (against nausea). Forbidden: coffee. culinary therapy	<b>Prayer:</b> Individual Hospital/community priest Religious community Prayer healer, long distance healer	
vitamins, minerals & antioxidants	<b>Other complementary self healing:</b> Nature, sporting activities, positivism, yoga, meditation, pets, bibliotherapy, sound therapy, self expression	<b>Other supplementary therapies:</b> Lymph therapy Immunotherapy Rosen method Hydrotherapy or hydrography

Figure 17. Complementary and alternative self-help therapies used by Finnish cancer patients

a similar way to folk medical treatments, we find nothing that would 'destroy' cancer directly among complementary medicine. These self-help treatments are meant to support cancer patients and give relief for various physical concerns. For example, the usage of cabbage and rhubarb leaves originates in Finnish folk medicine. These and other

leaves were commonly used to reduce infections in swollen places. The original objective of this kind of treatment was to ‘pull out the illness’. The particular cancer narrative that describes such treatment contains a warning, as the respondent burned herself when placing fresh leaves on her naked skin (435, see also 031). This was because acids from fresh leaves in spring can be dangerous, particularly if placed on wounded or sensitive skin.

Nevertheless, it has been fascinating to discover the tracks of culture-bound reasoning in cancer patients’ narratives, as this gives an insight into the discussion on self-help and alternative treatment. One interesting idea relates to strengthening the patient’s blood, two examples of which are given at the beginning of this chapter: drinking animal blood and getting a transfusion of Negro blood. Also categorisable under the heading *similia similibus curantur* could be drinking beetroot juice, which should ‘turn the weak blood red again’: “*Syö paljon punajuuria, niistä tulee punainen veri*” (474, see also 044, 275, 633). The use of garlic (or garlic extract) (066, 265) and onion (037, 410), are also evident as methods of blood strengthening. In traditional Finnish folk medicine the smell of onion and garlic, like the smell of pine needles (246) or extract (542), was often interpreted as having a purifying effect.

Birch tree ash, the use of which originates from folk medical practices (011, 224, 246, 275, 282, 286, 349, 455, 542, 547, 565, 627, etc.), was employed to strengthen and purify the patient’s body. The ash is a medicine that some patients prepare themselves, while others buy it in the form of pills from herbal remedy shops. Because the use of birch ash is widely discussed in cancer narratives, it is a good example of popular reasoning towards this and other complementary or alternative healing practices. As in other areas of life, there are two opposing parties, in this case those who are ready to try, use and suggest everything, and those who deny the possible help of such means. The majority of cancer patients, however, seem to be somewhere in between: they are ready to try, but they are not passionate about it:

*Lükuttavinta muuten oli sairauteni aikana, kun pääsin sairaalasta oli mieheni keittämässä tuhkalipeää minulle lääkkeeksi. Se oli kyllä hieno rakkaudenosoitus, mutta minä kehno vain nauroin, että siinä taitaa olla mukana rautaa ja hivenaineitakin. Meillä kun poltetaan kaikki vanhat, naulaiset laudanpätkätkin. Ei toki, hän oli puhdistanut saunan uunin ja hakenut puhtaita koivuja, se on puhdasta koivuntuhkalipeää. Joimme yhdessä ne lipeät, eikä siitä haittaakaan ollut.*

When I was ill the most touching moment was when I arrived home from the hospital and my husband was boiling birch ash for me. This was a truly beautiful sign of love, but I silly only laughed and said that there would be also some iron and minerals in it because we burn all old wooden pieces, even those including nails. No, he had cleaned the sauna oven and got some clean birch: this was clean birch ash. We drank it together and it did not harm. (627)

Drinking cognac and other strong alcoholic drinks also belongs to the strengthening category (see also 157, 205, 349). Cognac is typically consumed together with raw eggs in order to promote recovery:

*Taksikuski otti minut matkan varrelta kyytiin ja hän neuvoi minulle lääkkeen, joka vahvistaa ja pysyy sisällä. Hän ajoi viinakaupan eteen ja käski hakemaan konjakkia. Ja niin aloin käyttämään päivittäin lääkkeenä raakaa kanamunaa johon loraus konjakkia kyytipojaksi. Kontrollissa ihmettelivät, että sädehoidosta huolimatta veriarvot sen kun kohoaa, ja tunnustin mitä olen nauttinut, lääkäri myönsi, että se on ihan hyvä lääke, me ei vaan voida sitä määrätä potilaalle.*

The taxi driver picked me up and advised me of a medicine that makes you stronger and stays inside. He stopped in front of the alcohol shop and told me to get some Cognac. And so I began to use raw eggs with a nip of cognac every day. In the check-up they were wondering, as my blood rates were getting better despite the x-ray treatment, and then I admitted what I have used. The doctor told that this is a very good medicine, but unfortunately they cannot prescribe it to patients. (380)

## Mind-Body Medicine

The use of food and dietary supplements has a common place in the advice about cancer that spread to Finland at the beginning of 20<sup>th</sup> century. Foremost behind these ideas the Finnish-Swedish doctor Are Waerland (1876–1955) may be recognised. Waerland published several books dealing with the theme of cancer which contain suggestions on food intake and life habits, both as prevention and cure. His most famous book *In The Cauldron of Disease* was published in 1934 (Waerland 1934). His main health suggestions regarding cancer prevention concern the idea that people may improve their immune system by eating raw food and paying attention to their digestion. Waerland suggests that cancer is a lifestyle illness that has much to do with profession and social status. Accordingly, gardeners and peasants

living on farmsteads are far less confronted by cancer than fishermen, butchers and bar keepers, who inhale smoke, consume alcohol, and eat 'dead' food. The latter occupations are particularly affected by dangerous 'antropotoxines', which derive from the human body and make the air that those professions breath unhealthy (Waerland 1949, 34–38). To avoid cancer, or to become well again, Waerland suggests special diets that consist of raw food and milk products. According to his theory eating fish, meat and eggs is particularly dangerous. Furthermore, people should avoid hot coffee and hot meals as our insides do not have the protective skin that our bodies do. Above all, people should take care of their 'inner purity' by taking care of their digestive systems so that the food will not get 'stuck' in the stomach for a long time, where it might cause dangerous infections (Waerland 1949, 163–165). Waerland and his followers, sometimes called *the waerlandists*, were convinced that in addition to a vegetarian milk diet, water therapy and an active lifestyle guarantee health (Lehtonen 2003). Apparently, Waerland's theories have had immense impact on popular reasoning about healthy eating and living. Naturally, popular knowledge does not derive directly from Waerland's books, but initially from various newspaper articles and essays, and subsequently from writing that reflects similar ideas.

The following example, which describes events that took place in 1984, might remind us of legends of miraculous recovery, although telling such stories is not uncommon among cancer patients:

*Kotona olin vielä kauan todella huonokuntoinen. Minun piti myös ratkaista ongelma, miten tästä eteenpäin. Päättelin, että jos vielä otan sitä myrkyä, menehdyn siihen, mutta jos lopetan hoidon kesken, lopputulos on ihan sama, tieni vain saattaisi olla pitempi ja kivuliaampi. Yksi hoitokerta jäi jo väliin ja seuraavakin läheni uhkaavasti enkä vielä ollut tehnyt päätöstäni. En osannut. Vihdoin tajusin tuoda ongelmani Jumalalle. Pyysin, että Hän osoittaisi minulle sen tien, jota Hän halusi minun kulkevan ja niin selvästi, että ymmärtäisin. Juuri silloin ovikello soi ja samassa jo eteisestä kuului tuttu ääni: "Hei, onko täällä ketään kotona?" Eteiseen päästyäni sain käsiini Elsa Ervamaan kirjan Elävä ravinto ja pussillisen vehnäjyviä. "Ja nyt kokeilet tätä, kuului komento." Joskus Jumala vastaa todella nopeasti! Ja ihanasti. Ja vakuuttavasti. Vehnäjyvät olivat jo itämässä ja olin innolla opettelemassa muista Elävän ravinnon alkeita, kun sain kirjeen Kanadasta. Serkkuni oli huolissaan kuultuaan hoidostani. "Lopeta heti se solumyrkkyhoito ja etsi käsiisi tietoa elävästä ravinnosta," oli hänen kirjeensä ydinsanoma. Olin saanut vahvistuksen asialle. Kumpikaan näistä Jumalan airuista*

*ei tiennyt verenmyrkytyksestäni. Sädehoitopkl:lla kerroin päätökses-  
täni: enää en ottaisi solumyrkkyä, vaan siirtyisin Elävään ravintoon.  
Lääkäri sanoi, että saan kyllä vapaasti valita, mutta noin suuri syöpä  
ei sillä parane. Saisin kuitenkin tulla takaisin milloin vain haluan ja  
kontrollissa kävisin säännöllisesti joka tapauksessa. Olin helpottunut.  
Olin pelännyt hänen suuttuvan. Alku oli hankala, kaikki piti opetella  
kirjan ohjeiden mukaan ja muulle perheelle piti tietenkin laittaa ta-  
vallista ruokaa. Kun myrkyt läksivät liikkeelle elimistöstä, se aiheutti  
väsymystä. Paino putosi jatkuvasti. Monta kertaa olin niin uuvuksissa,  
että aioin lopettaa, mutta aina silloin joku ystävä toi jonkun uuden  
kirjan ja rohkaisi jatkamaan. Vasta syksyllä voimat alkoivat vähitellen  
palautua. Jaksoin käydä kävelyllä ja voimistellenkin kuntouttaa jalkaa-  
ni, oikein paneuduin itseni hoitamiseen. [---] Kevättalvella hiihtelin ja  
kuntoni kohosi. Söin dieettini lisäksi vähän voileipää ja painoni nousi  
53 kiloon. Keväällä, vuosi elämänmuutoksen jälkeen pyysin lääkäriä  
mittaamaan kasvaimeni koon. Hän ei löytänyt sitä enää. "Siihen voi  
olla kaksi syytä," hän kiirehti selittämään. "Ensinnäkin, syöpäsolut ovat  
voineet kuolla jo sytostaattihoidon aikana ja sen jälkeen elimistö on  
pikkuhiljaa poistanut ne kehosta. Toinen syy saattaa sitten olla se elävä  
ravinto. Yllättävän hyvin joka tapauksessa on mennyt!*

At home I felt sick for a long time. I had to make a decision about how to continue from here. I decided that if I take more of this poison, I will die from it, but if I stop the treatment the result is exactly the same, my path could be perhaps longer and full of pain. I had missed one treatment already and the next one was coming closer and I had not made up my mind. I could not. Finally I decided to share my problem with God. I asked him to show me the path that he wants me to follow so clearly that I would understand it. At the same moment the doorbell rang and from the hall came a familiar voice: "Hi, is there someone at home?" As I got to the hall I was handed the book written by Ella Ervamaa: *Living Food and the Sack of Seeds*. "And now you will try it," I heard the command. Sometimes God answers really fast! And in a nice way. And in a convincing way. I had already planted the seeds and was studying other things regarding living food when I received a letter from Canada. My cousin had heard about my treatments and was concerned. "Stop immediately taking this cell poison and find out everything about living food," was the main message of her letter. I had received a confirmation of the issue. None of those messengers from God knew about my blood poisoning. In the hospital I told them about my decision: I will not take chemotherapy any more and will continue with living food. The doctor told me that I can choose freely, but such a large cancer will certainly not be cured like this. I was expected to come back whenever I wanted and I should visit the tests regularly anyway. I was relieved. I was afraid that the doctor would be mad at me. The

beginning was difficult as everything was done according to the instructions written in the book and the rest of the family expected to get their normal meals. As the poisons began to leave the body I felt tired. I lost weight. Several times I was so exhausted that I decided to stop, but then some friend again brought some new book and encouraged me to continue. Yet, in the autumn I felt the strength coming back into my body. I had the power to walk and make some exercises with my foot. I was dedicated to taking care of myself. [---] In winter I went skiing and I got fitter. In addition to my diet I ate some sandwiches and I put on some weight. In spring, a year after the big change, I asked the doctor to measure the size of my growth. He did not find it anymore. "There may be two reasons," he eagerly explained: "First of all the cancer cells died already at the time of chemotherapy and then your body has removed them slowly. The other reason could be the living food. Anyway, things have gone surprisingly well!" (520)

From the cancer narratives we find numerous similar success stories about the results of self-help. As these stories are represented in the cancer narratives, they take on another significance as well. Unlike the legends of miraculous healing that are normally presented without extended context, entrants to the writing competition admit that such a big change in life can be really exhausting and time consuming. Although many people agree that the change has a positive impact on their bodies, finding and preparing appropriate food takes lots of effort. As with the story quoted above, the decision to give up biomedical treatments is not easy, whereas combining the two methods seems impossible. The first reason is connected with the societal expectation that every cancer patient should be treated in the hospital according to the socially accepted healing traditions of scientific medicine. The second reason is that various alternative therapists demand an immediate stop to biomedical treatments. The final decision makers, under such circumstances, are naturally the cancer patients, who generally expect something less radical, hoping to combine both methods to achieve a positive outcome. However, when the alternative path is chosen, which is normally after the biomedical treatments are finished or if they are unsuccessful, people admit that after some time they tire of it and return to their normal lifestyle and eating habits, although they perhaps pay more attention to what they consume (006, 018, 033, 037, 044, 066, 100, etc.).



## Energy medicine

When discussing the reasons for falling ill, people often made a link with their individual thinking and behaviour. In order to become well again they try to think more positively and do things that would bring some positive energy into their lives (046, 056, 125, 184, etc.). This could be described as attempting to balance one's psychological concerns. However, the means to achieve the desired balance can be widely different. The treatments of energy medicine resemble the aims of mind-body medicine. People search for lost vitality. The necessary energy may be received via healing hands, anointing rituals or by calling a long distance healer. Different supplementary therapies offered by various licensed and unlicensed practitioners come under the heading of energy medicine. According to the pathographies studied here, the main advantage of the various supplementary therapies is that practitioners take their time to care for patients holistically, considering both the physical and spiritual concerns. Naturally, such support may also come from any person who has a special relationship with the cancer patient: *"Uskon, että paras lääke sairastuessaan on toinen ihminen ja usko vakaa ajatus että paranen ja haluan"*, "I believe that the best medicine if one has fallen ill is another person and a strong belief that I will get better – and I want it" (046). In this vein many patients make use of cancer support, provided either by communicating with the support person or by visiting a rehab campus for cancer patients. Of similar importance are religious groups in which the patient is supported by individual or collective prayer:

*Mutta eräänä päivänä hän soitti minulle ja pyysi minua kanssaan ajelulle naapuripitäjään. Ihmettelin, kuinka hän saattoi niin kuumeisena ja huonokuntoisena lähteä sairaalasta. Hän selitti saaneensa lääkäriltä luvan. Vävyimme haki hänet ja menimme eräeseen rukoukokoukseen. Siellä hän meni horjuen eteen ja pyysi, että hänen puolestaan pyydetäisiin Jumalalta apua. Minä istuin penkissä ja olin rukouksessa mukana itsekin. Mieheni tuli mun luo ja silmät loistivat kirkkaana. Suu hymyssä hän kertoi tunteneensa, että kaikki syöpä lähti hänestä pois. Se oli valtava tunne, näin hän kertoi. [--] Ruumiinavauksessa todettiin, ettei hänellä ollut mitään syöpään viittaavaa, sydän oli kuitistunut. Siellä oli ollut nestettä paljon ja kauan aikaa, mutta sitä ei ollut havaittu aikaisemmin.*

One day he called me and asked me to join him travelling to a neighbouring county. I wondered how he could leave hospital being so ill. He

explained that the doctor allowed him. Our son-in-law took him and we went to a certain prayer meeting. There he went trembling in front of all the people and asked them to pray for him and pray for God's help. I sat on my bench and prayed as well. My husband came to me eyes sparkling bright. Smiling he told me how he had felt cancer departing from his body. It felt great, he said. [---] During the autopsy they did not find any cancer. His heart had shrunk. There had been lots of liquid in it for a long time, but they had not discovered it before. (167)

Searching for additional spiritual power from religion and prayer seems to be common for many Finnish cancer patients (see also Ahmadi 2006, 47–50). This appears particularly significant in comparison to Estonian cancer patients. The latter rarely adopt the structures of Christianity in their cancer stories and interpret their illness more as individual destiny. For example, in the internet forum for Finnish cancer patients the Christians and non-believers clearly form two groups who argue about their illness process using two different paradigms. For Christians, the pathological drama is also a path by which to negotiate their individual lives as Christians. If people trust that they have spent their lives in accordance with biblical truths, it becomes easier to accept the illness process. Others, who interpret their lives as not having been lived in accordance with Christian thought, find the idea that cancer is God's punishment appears as terrifying. The fear and hesitation deriving from Christian thought is particularly meaningful in the narratives composed by older men. They hope for forgiveness, while at the same time are still concerned about their status after death, and therefore accepting the idea of dying is very complicated.

Because of the agricultural roots of the Finnish population, the countryside and forest as natural surroundings have a particular significance. This also means that to practice self-healing rituals, people return to the countryside and the forest in order to regain their lost selves. Accordingly, in numerous contributions to the writing competition people are sure that in the countryside they can enjoy nature and receive nature's balancing and healing power: *Leikkaushaava aristi kyllä joka askeleella ja sienikori painoi, mutta luotin metsäluonnon parantavaan voimaan*, "The surgery wound was still really tender when I walked, and the mushroom basket felt heavy in my hand, but I believed in the healing power of the forest" (033).

Above all, searching for spiritual support from nature may be interpreted as an act of regaining one's lost identity. As comparing oneself with other people seems impossible, the forest and nature represent spaces where people can be as weak and wounded as they like, without being judged by others. Being in a natural environment does not heal immediately, but the possibility to face personal change within natural surroundings is often represented as a key moment in understanding the central role of self-help:

*Tehtyäni aikani tätä surutyötä – ajattelin, että eihän tämä tästä ainaakaan tällä tavalla parane vaan rasitan vain itseäni. Joten päätin että nyt on otettava itseään niskasta kiinni ja ryhdistyttävä. Aivan ihmeen kaupalla näin valoa elämässä, ajattelin niin kuin aiemmat potilaani, että tämä kuuluu minun elämäni joka ei ole omissa käsissäni, siinä välikädessä ovat lääkärit ja itse elämän antaja. Hyväksyin itselleni kummankin vaihtoehdon, joko kuoleman tai mahdollisen elämän jatkuvuuden, eikä se tuntunut ensinkään vaikealta tuon valtavan surutyön jälkeen.*

After mourning for a long time I thought that my life will not get better like this and I will only make my condition worse. Thus, I decided to get a grip on myself. As a miracle, I saw some light in my life. Like my patients before, I realised that this belongs in my life – that it is not in my hands. In between stand doctors and the creator of life. I accepted both options for myself, either death or possible continuation of life, and it did not feel bad at all after such a long mourning process. (184)

## **Basic concerns and problems with using complementary treatments**

The public discussion about complementary and alternative treatments remains to this day either non-existent or very loaded. Therefore, we also find among cancer patients many who experienced complementary and alternative therapies as being somewhat problematic or ineffective. Cancer patients' reasons for choosing, or not choosing, complementary or alternative treatments is a good example of the public discussion, and of sociocultural attitudes towards non-conventional cures in Finnish society. Some patients are not satisfied with the fact that alternative treatments are not covered by health insurance. Others wish that they could openly combine various treatments. Above all, people seem very suspicious of the use of unconventional therapies, as during past

decades they have learned that complementary and alternative treatments, like ethnomedical practices, are considered useless hocus-pocus. The following are some of the main concerns about non-conventional treatments, as expressed in the cancer narratives.

First of all, complementary and alternative treatments are expensive and time-consuming:

*Sädehoidon alkua odotellessa kävin vaihtoehtolääkärillä. Hän teetti erittäin laajan veritestin, sekä määräsi mahtavan määrän luontais/ apteekki pillereitä, mutta ehdottomasti vain tukihoitona sädehoidon ohella. Tämä tuli kyllä aikalailta kalliiksi, koska sairausvakuutus ei korvaa näitä kokeita eikä kaikkia lääkkeitä. Ehkä siinä oli hieman lääkärinkin puolelta jo rahastuksen makua, joten en jatkannut käyntejäni hänen vastaanotollaan.*

While I waited for chemotherapy I visited an alternative doctor. He made very accurate blood tests and prescribed an enormous amount of natural and pharmaceutical pills. He said that these are meant only to support the conventional treatments. It was very expensive, as health insurance does not cover these tests and drugs. I was also left with the feeling that the doctor just wanted to make money, so I did not continue my visits to him. (066)

Secondly, complementary and alternative treatments cannot be openly incorporated into conventional treatments:

*Alkoi kamppailu elinajasta. HYKS:in hoito oli tehokasta ja hyvää. Omaisten voimavaroja ja alati orastavaa toivoaa riitti valitsemaan vaihtoehtohoidoksi kliinisen hoitomuodon rinnalle Kaarlo Jaakkolan vitamiini- ja hivenainehoito. Jäin kaipamaan HYKS:iinkin puolueetonta henkilö, joka voisi kertoa erialisista vaihtoehtohoitomuodoista, ettei yksittäisten sairaanhoitajien tarvitsisi kuiskalla niistä vaiivhkaa, kun omaiset hädässään tiukkaavat kaikkea mahdollista apua rakkaalleen.*

I began to fight for my life. The hospital treatment was sufficient and good. Family and close friends wanted something more and so we decided to use vitamins and mineral therapy. I missed somebody at the hospital who was unbiased and could explain alternative methods to me – nurses should not whisper and hint about these treatments when people search for possibilities to help their loved one. (288)

Thirdly, complementary and alternative treatments are not reliable enough:

*Kaikenlaista luontaistuote parannuskeinoa ovat monet tutut ja lähes tunte mattomatkkin suosittelleet syöpääni. Yksi veljeni ja kaksi sisarta-*

*nikin ovat soitelleet ja kirjoitelleet luontaishoidoista ja ihmetohtoreista jotka ovat sen ja sen saaneet parantumaan. Eräs kaukoparantajakin soitti (en tunne koko miestä) ja kysyi saisiko hän alkaa minua kaukoparantamaan. Eihän minulla tietenkään ollut mitään sitä vastaan. Mieli teki kyllä sanoa etten oikein luota sellaiseen hommaan vaan en halunnut loukata.*

Acquaintances and strangers alike suggested all kinds of natural treatments to heal my cancer. One brother and two sisters have called and written to me about natural cures and ‘wonder doctors’ who have healed various people. One long distance healer called and asked if he could help. I had nothing against it. I wanted to say that I do not believe in it at all, but I could not hurt his feelings. (508)

Fourthly, complementary and alternative treatments are not efficient enough:

*Sain kirjan itseparannuksesta. Kaikki ohjeet kelpaavat tähän tilanteeseen. Kokeilen kirjan oppia, panen käteni kipeälle paikalle ja sanon, parannu pian, parannu pian. Olen silti yhtä kipeä. [---] Luonnontuotteet alkavat kiinnostaa minua, vaikka olenkin aina ollut oikein lihansyöjä. [---] Saan uuden vihjeen, joka kuulemma on tunnettu kansanparannuskeino kipeisiin paikkoihin. Tietenkin kokeilen myös sitä. Vihreän kaalinpään lehtiä pannaan kipeisiin kohtiin ja niinhän siinä kävi kuin olin uskonutkin, ei se mitään auttanut.*

I got a book about self healing. All instruction is useful in my situation. I try out what they suggest in the book: I put my hand on the ill place and say: “Become well soon, become well soon.” I am still as ill as I was. [...] Natural products are interesting for me, even if I have eaten meat all my life. [...] I get a new tip that is a well known folk medical treatment against the ache. Of course I try it as well. I place green cabbage leaves on the ill place and it goes as I believed – it did not help at all. (031)

Fifthly, complementary and alternative treatments are a marketing trick to fool desperate people and make money:

*On tietenkin helppo suhtautua kriittisesti näihin ilmiöihin, samoin kuin täällä hetkellä paljon esillä oleviin antioksidentteihin sekä vitamiini- ja hivenainehoitoihin kun oma kokemus koululääketieteestä on niin positiivinen. Voin kuitenkin kuvitella, että itsekin voisin takertua mihin oljenkorteen tahansa jos tilanteeni olisi toivoton, joten potilaita ei pidä moittia. Moitittavia ovat sen sijaan sellaiset piirit, jotka tietoisesti käyttävät hyväksi ihmisten hädänalaista tilannetta pelkän rahastamisen mielessä.*

It is easy to be critical towards these [alternative] treatments, as well as anti-oxidant, vitamin and mineral cures popular at the moment, if my personal experience of conventional treatment is so positive. I can however imagine myself using all available methods if my state was hopeless. Therefore, I think patients should not be admonished for using that. Rather, those who take advantage of people's desperation in order to make money should be admonished. (147)

However, even those cancer patients who have expressed real scepticism towards all non-conventional treatment still have some personal experiences, either negative or positive, of the subject. The discussion about the use of complementary and alternative medicine in cancer narratives emphasises the general need for openness concerning the use of complementary and alternative treatments. Beyond this need we may detect something even more important. The patient's need to be taken notice of and treated as an individual, rather than a non-human diseased body, during the illness process. As patients do not receive the desired attention they are prepared to go through the 'rites of passage' in order to get well as accepted on the societal plane.

Cancer patients' writings show that people are rather bad at following health instructions when they do not find them useful or suitable to their condition. Something that applies both to following the biomedical instructions from physicians, and to the prescriptions of so-called 'vitamin and mineral doctors' and other alternative therapists, who in their private practices make blood tests and screenings and prescribe large quantities of pills that to improve cancer patients' general conditions (059, 268, 288, 569). Alternative and complementary self-help instructions from others may be seen as useful and be adopted with enthusiasm for a time, however, people often give up some time later. This happens mainly when they find out that to cope with cancer and have the strength to move onwards with their lives, they have to regain their previous trust in themselves. This also means believing in the self-help methods that feel good and, in the individual's opinion, help with recovery.

## Conclusions

The debate about choosing, or not choosing, complementary and alternative self-help methods has a significant role in the cancer narratives. First of all, general discussion therein emphasises the role of

an individual as a norm breaker or as a socioculturally stigmatised disease carrier. Secondly, cancer narratives point out the desire to be well again. Because the setting of the pathological drama is different for every cancer patient, there is also no consensus about using complementary and alternative treatments among them. However, cancer narratives indicate that people who have learned responsibility for their physical condition, appreciate the opportunity to be an active participant in the treatment process. Thus, as long as the conventional healthcare system continues to take care of dysfunctions at the cellular level, ignoring patient's other needs, people continue searching for complementary and alternative treatments in the hope of improving their health.

The main concern among Finnish cancer patients is their fear of discussing complementary and alternative treatments with their doctors. Medical practitioners, who are trained to trust only evidence-based medicine, wish to avoid the subject. This causes concern and uncertainty among cancer patients, as in general they would like to agree with the doctor's expertise. Conversely, as people are used to taking care of their primary health concerns by themselves, they can decide to use traditional or non-conventional self-help therapies in addition to cancer treatments prescribed by doctors. Whatever the chosen treatment is, its aim is primarily self-help and ultimately recovery.

Above all, the use of self-help treatments among Finnish cancer patients indicates that illness cannot be separated from the person. The greatest benefit of non-conventional medicine is, therefore, that it does not concentrate only on curing cancer, but also on healing the sick person as a whole. This kind of need for a holistic approach appears to be very significant for cancer patients, who suffer not only from their illness but also from various domestic, work and relationship problems. According to the narratives analysed here, complementary therapies help people resolve their individual problems, they offer some of the support and hope for which patients so desperately yearn. In addition, cancer patients see the treatments listed above as purifying and energy providing. Occasionally, alternative treatments become a last ditch effort, either for the patients or for their friends and relatives.

# WRITTEN CANCER NARRATIVES

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

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