

***Looking at Life through a Mask:***  
*An Autoethnographic Journey into the Worlds  
of Cancer*

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## *Japanese - English Glossary*

Atsui – hot

Atatakai –warm

Boku – me, often said by a male

Daini-nokanja – a relative to a patient

Dokokana – “(I am wondering) where?”

Gan Pea Sapoutasu – cancer peer supporters

Hakushin-no-engi – acting realistically

Heiso – walking side by side

Ikizama – one’s attitude towards life

Ikuru – to live

Ikiterukanja-wa-mitakunai – “I do not want to see a (cancer) patient who is still alive”

Iku-furi – pretending to join

Joge-kankei – a hierarchical or vertical relationship

Kohai – a junior of a sempai

Kihon-no-shisei – basic posture for listening

Kokoro – Japanese notion of mind, heart or feeling

Kyokan – Japanese notion of empathy, newer word than omoiyaru

Ma – “interval” in space and time or the state of being “in-between”

Maemuki – facing forward

Maitsutana – I do not know what to do

Okusan-no-okimochi-wa-do-desuka – how does she feel about this?

Omae – rude way of addressing someone as you

Omoiyari – traditional Japanese notion of empathy

Omotenashi – welcoming gesture

Onigiri – A rice ball (for a meal)

Oyaseni-narimashita-ka – Have you lost your weight?

Rigai-kankei – stakeholder

Samue – the work outfit of a monk

Samurai – warrior from the feudal time in Japan

Sasou-furi – Pretending to invite someone



Satsuru – sensing, guessing

Sempai – mentor

Shiranai-furi – pretending not to know

Shisei – posture, as well as an attitude towards something

Sodesu-ka – expression of understanding

Sodesu-yone – alternative way of expressing understanding

Tezukuri-bento – a handmade lunch

Tou-satsu – secretly taking a photo or video without permission

Tsumetai – cold

Tsutsumi-komareta-youna-kimochi – the feeling of being warmly taken care of

# Abstract

## ***Looking at Life through a Mask: An Autoethnographic Journey into the Worlds of Cancer***

Shotaro Wake

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This thesis explores the intersection of observational filmmaking with auto-ethnographic writing, a combination not used very often but with great potential for visual anthropologists. I examine how my research and filmmaking over a ten-year period have been shaped both by my cancer experience as well as by my Japanese background. Using the metaphor “journey”, I approach my own traumatic cancer experience and turn it into a field of study. My journey begins from the moment of my first cancer diagnosis and treatment in the US, moving through my second diagnosis in Norway, and leading up to my most recent fieldwork with a cancer support community in Japan. My auto-ethnographic journey illustrates how I altered my own relationship to my cancer, moving through critical encounters that transformed me from a silent sufferer to an attentive listener. These experiences have also influenced my metaphorical thinking about “dying well” to “living well” with cancer.

My personal journey is closely linked to my professional one, and also affects my approaches to filmmaking. By meeting the anthropologist Paul Stoller, who has also lived in the world of cancer, I learned the importance of coming to terms with one’s own cancer mask. This mask can easily evoke a sense of being trapped in a “continuous liminality” (Stoller 2005), a transitional state between health and sickness, hopefulness and hopelessness, past and future, life and death. How am I able, as a researcher and filmmaker, to go on with my life in this in-between state and attend to the lives of others through this cancer mask? In my recent fieldwork, I decided to enter the world of the cancer patients’ shadow and met with the families of patients and bereaved families in a support group in Japan. I learned that they too wore a mask, though I struggled to establish friendships with them as my cancer status versus their caregiver status distanced us somewhat. I overcame this challenge by using the technique of collaborative filmmaking to seek mutual fellowship with them, and trying to create a shared space in-between, *ma* in Japanese, where we could meet and feel with each other (*kyokan* empathy). For that purpose, and combined with the technique of feedback screening, I used a mobile phone as a filming device to free up my face and to make me available as a listener for the filmed persons. The fieldwork resulted in the film *To the Last Drop* (2016).

By combining the methods of auto-ethnographic writing and observational filmmaking, my personal account served to broaden my understanding of the experiences of those afflicted by cancer in Japan. Together, these methods expand on the space between, where suffering becomes visible and silence becomes audible, in a culturally sensitive way.

## *Declaration*

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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## *Film Synopsis*

### *To the Last Drop* (2016)



Mr. Okamoto-san is driven in his quest for the perfect cup of tea. He is trying to cope with his wife's cancer diagnosis and joins a support group for empathy and companionship. By way of repaying the kindness, he insists on serving tea and coffee at all of their regular meetings. His efforts bemuse as much as comfort these fellow travellers on their painful journeys. But by being useful he knows that he can find a certain relief, may even find things to smile about along the way. ***To the Last Drop*** is filmed using a smart-phone rig to minimise the disruption of the process. From the filmmaker's own personal experience of cancer, he is a friend of Okamoto-san's through difficult times, attentive to his story and all his small gestures of defiance when facing the inevitable.

I recommend watching the film at this point or before reading Chapter 4.

Click the link to watch the film: [To the Last Drop \(2016\)](#)

Password for viewing: 5678



## *Prologue*

An epilogue of one story is the prologue of another: Six and a half years have passed since my second cancer treatment, which I underwent while I was writing up my master's thesis and editing the film based on my fieldwork of a year earlier in 2009. I chose to do my fieldwork in my hometown, Shizuoka, in Japan. I joined and participated in a local cancer support group, Ippo Ippo (Step by Step), not only as a researcher but also as a former cancer patient. I became their latest cancer member. In my master's thesis, I inserted a tiny epilogue in the conclusion explaining that I had been diagnosed with recurrent cancer in Tromsø, Norway. In the midst of this difficult time, the group members sent me emails and video messages. In the conclusion I briefly mentioned that their empathic gestures encouraged me to undergo my second cancer treatment, enduring chemo and radiation therapy and their tough side-effects (Wake, 2010, pp. 52-53). However, the scope of that thesis did not allow me to fully elaborate what it meant for me to receive these messages in the midst of a personal catastrophe. In the middle of writing this PhD thesis, I read the epilogue again, and I came to see that it contains all the elements that have shaped my research interests in the years that followed; it was the foundation for my autoethnographic approach, as well as the course of my most recent fieldwork for my PhD. It is time to let out all the elements that have been waiting to be rediscovered, and I will use them as a point of departure for my new journey in the worlds of cancer.



## *Introduction*

Cancer is not one disease but many diseases. We call them all “cancer” because they share a fundamental feature: the abnormal growth of cells. And beyond the biological commonality, there are deep cultural and political themes that run through the various incarnations of cancer to justify a unifying narrative. It is not possible to consider the stories of every variant of cancer (Mukherjee, 2011, p. xvii).

In biomedicine, cancer is now organised in over 200 different subcategories. Treatment plans and its prognosis may vary in terms of type, stages, age, gender, physical and health conditions as well as lifestyle (Cancer Research UK, n.d.). Cancer in this sense is a polythetic term, and although no one characteristic or feature is shared by everyone who has cancer, as a group it forms a kind of identity. Needham’s words underline the complexity of this identity: “[a]mong the members... there is a complex network of similarities overlapping and criss-crossing; sometimes overall similarities, sometimes similarities of detail” (1975, p. 350). So a simple question is what unifies these people? Is it just the word cancer or something else related to it?

In many ways what represents people with cancer is the necessary emphasis put upon the notion of uncertainty. Uncertainty locates people on the border in multiple ways, between knowing and not knowing, certainty and uncertainty, past and future, and ability and inability. Moreover, people constantly oscillate on the border. Receiving a cancer diagnosis can be read as a critical event in which pre-existing ways of thinking and being may undergo substantial transformation, for example in relation to the perception of self/other, body, social relationships, religious belief, everyday practice, moral values and so on. Yet, persons come with pasts - they carry certain values and worldviews closely attached to how they have lived their lives. Therefore, there are bound to be a diverse range of responses to cancer diagnosis, relating to how one is able to cope with unpredictable and frightening life situations. It is crucial for

anthropologists to focus on the ever changing, fluid dynamics of lived experience and the lives of people confronting serious illness, instead of focusing on a fixed and static representation and positionality such as that of the “sick role” (Parsons, 1975). This project will endeavour to take a dynamic focus.

Based on her fieldwork in Uganda, Susan Reynolds Whyte (1997) argues that uncertainty requires a pragmatic focus on action. It opens up both a “trying out” of behaviours and alternative courses of action. However, it also underlines that there are no standard guidelines for choosing the correct response toward a particular problem. Nevertheless, she continues that this is also what allows for an imagining of possibilities that gives rise to hope. Thus, uncertainty is not closed or locked but an ambiguous, open space for interpretation where people come up with explanations and negotiate meaning(s) through their creativity, imagination, and emotions. This space could be called an “explanatory gap” in which people creatively develop their own explanations in order to make sense of their situations. Narratives are one of the most important means by which we fill the explanatory gap and create meaning between what we know and what we don’t, as well as to understand the unexplained, the ruptures and the disruptions.

These narratives are constantly being constructed as we always search for meaning and continuity, especially when faced with illness, pain and suffering (Kleinman, 1980; Book, 1988; Becker, 1997). Byron Good (1993) argues that narratives of suffering are negotiated through dialogue between individuals and are therefore intersubjective enterprises between families, friends and communities. These narratives rely upon shared ground and are affected by limitations in social, religious and scientific discourse allowing space for questioning, rationalising, interpreting and theorising to take place, making room for different perspectives (Kleinman, 1980; Book, 1988; Becker, 1997). It may be that the unifying element of cancer arrives at the moment these narratives are communicated orally and through the body. How are anthropologists able to listen to these important narratives and sufficiently grasp what it is to live in such an uncertain world as the one brought about by cancer?

However, Arthur Frank warns us that we have to bear in mind the question of whose story it is (1995). For instance, as Byron Good (1993) and others point out, “a therapeutic narrative” is made between the oncologist, the patient, and their families, and although employing narrative for mutuality is the ideal, a patient’s illness narrative tends to be driven by the oncologist who has the knowledge and power in the relationship. This can be a problem for the patient as the oncologist moves on as soon as the patient has finished their treatment (Frank, 1995). Thus, the patient is left with their wounded, medically colonised body and illness narrative. Based on this line of thinking, Arthur Frank encourages us to help sufferers claim authorship of their own illness narrative. He believes this is possible through listening, because “in listening for the other, we listen for ourselves. The moment of witness in the story crystallizes a mutuality of need, when each is for the other” (ibid, p. 25). Moreover, an important prerequisite for this to work is that the wounded storytellers also engage their listeners by allowing them to comfortably attend to the stories they tell (Crapanzano, 1994). It is indeed a challenge for both parties as “telling does not come easy, and neither does listening” (Frank 1995, p. xii). In this thesis I will explore how the anthropologist can actively help build mutuality between the storyteller and the listener through various forms of communication in the field.

In trying to understand cancer, I realised I had to listen to my own cancer narrative. I am not the first researcher to be interested in my own illness story. Indeed, I can draw on several excellent examples. Major figures such as Robert Murphy (1987), Arthur Frank (1995), and Paul Stoller (2004; 2009a; 2009b; 2012; 2013) all turned their narrative illness into research projects. I admire the way they have approached this difficult topic, not only academically but also personally. Their work could be considered as adopting an auto-ethnographic approach. According to Carolyn Ellis (2004), a leading researcher in this field, auto-ethnography is “research, writing, story, and method that connect the autobiographical and personal to the cultural, social, and political” (p. xix). The ethnographer is encouraged to make use of his or her own subjective account and not only to understand the self, but also others in the realm of intersubjectivity in which “knowledge and insight can be shared between individuals” (van der Geest, Gerrits and Singer Aaslid, 2012, p. 6). In addition, I argue that the

focus is on how an ethnographer's own knowledge and insight are not fixed but fluid, constantly changing through ongoing interaction with others.

Delving into stories of illness is difficult, especially when you have undergone an illness experience yourself. Having a serious illness like cancer elicits strong emotions in people such as, fear, anger, worry and sorrow. Through my personal experience as well as my fieldwork working with people afflicted by cancer, I have witnessed and shared very personal matters imbued with suffering and pain. Ethically, there is a fine line between what one can ask people to reveal about such personal matters, and what one should expect to be kept private. The advantage of the auto-ethnographic approach is that I am able to use myself as a subject and put myself in a vulnerable place by entering into sensitive matters. In this way I am able to go deep into feelings such as anxiety; not an unusual feeling among those afflicted by cancer, and something I used to see as a weakness. Having the starting point in myself, I could thus respectfully make use of my own cancer story and highlight its connection, resonance, and dissonance to the people I met, presenting an insight into what it is like to live with cancer. In addition, through filmmaking I tried to explore sensitive matters that are difficult to talk about, particularly through showing how people are sensitive to each other when they relate via their experiences with cancer. The writing would not have been able to expand beyond my own story if I had not made the film. In this view, the text and the film complement each other, enriching my auto-ethnographic journey.

Interestingly, it was not my plan to adopt an auto-ethnographic style when I began writing my thesis. As I further explored my own experiences through writing, I realised it did not feel right to use the voice of the third person. During the process, my narrative began to look like a journey. According to Nie and his colleagues (2016), since the start of the 20<sup>th</sup> century, the use of military metaphors has been central to describing illness. However, they argue that using the journey as a metaphor can provide an alternative and inspire acceptance and meaningfulness. Throughout my 13 years of cancer, I have myself gone through this metaphoric shift. If I had started the writing process at the time of my first treatment in the US, I would have used the metaphors of “fight” or “survive”, since those were the ones I felt best described the

path I had to take. However, today I know that using a metaphor of war would not help me become tolerant or accepting of the situation. According to Lakoff and Johnson (2008), in their *Metaphors We Live By*, the choice of metaphor people make in their narratives has a significant impact on them:

Metaphors may create realities for us, especially social realities. A metaphor may thus be a guide for future action. Such actions will, of course, fit the metaphor. This will, in turn, reinforce the power of the metaphor to make experience coherent. In this sense metaphors can be self-fulfilling prophecies (p. 156).

From this perspective, using the metaphor of the journey has cultivated my attitude as a researcher towards a more peaceful way of looking at my own cancer experiences. And through such a journey I was able to listen attentively to others and their cancer experiences, which has become the theme of this auto-ethnographic thesis.

Having chosen the auto-ethnographic path to writing, from the beginning I had to ask the following question: How do I work with memory? Memory can easily become blurred through reflective ethnography in the boundary between the self of the past and that of the present. The boundary is blurred because as I interpret my memory, it changes its meaning depending on my emotional state. Furthermore, it influences how I see memories in relation to the present as well as the coming future. In this sense, memory is always unstable or “malleable; it is a social process, through which past events are interpreted” (Svašek, 2014, p. 151). My memory around the time of cancer is something I try not to think about in detail as it requires a lot of energy and provokes unpleasant and anxious feelings when I do so. Nevertheless, the memories have a presence; they are harboured inside me with a heavy sense of weight, frequently distracting my attention away from the present. Consciously I do not have much control over these memories, and sometimes they are provoked or appear through association with something else in my daily life, implying how we are only partial agents even with regard to the content and character of our own thought processes. By deliberately trying to write, I was expecting to meet these more or less suppressed feelings from the time of my cancer again. According to Jon Kabat-Zinn, (2013), an influential academic on mindfulness, the author of *Full Catastrophe Living* and

founder of MBSR (the Mindful Based Stress Reduction method), suppressing feelings is a way of handling stress, although it can also create a negative feedback loop. People often try to avoid experiencing unpleasant emotions, and may develop unhealthy behaviours to avoid it (turning to alcohol, chemical substances, etc.). Having chosen to follow the worlds of cancer, I am ready to take these memories and feelings out into the light in order to examine, analyse, and reorganise them. Perhaps dealing with my traumatic memories in an academic setting will make it somewhat easier to create some distance. However, even with this academic tool in hand, I still know that it will be difficult. Even when I try to remember, I have difficulty in recalling certain details. This makes itself apparent when I compare my memories to the memories of my Norwegian girlfriend, and wife since 2011, Hedvig. We were both at the oncologist's office on the day I received the cancer diagnosis in Norway. I will highlight the memory gap between us in Chapter 2. Here it is sufficient to say that the gap was quite big. Clearly more took place in my life at that time than I can recall, so what are these gaps in my memory and how do they come about? Are they spots of suppression as a way of avoiding stress? It may not be about something traumatic at all. People do forget memories as time goes by. It has been over ten years since my first diagnosis in the US, and more than six years since the second time in Norway. Still, I am far from being at peace. There is something deep within that bothers me and affects the quality of my everyday life. I have a desire to seek an explanation for my traumatic experiences.

These gaps are an important issue for researchers interested in the subject of memory, including myself, and especially when dealing directly with one's own traumatic memories. How can one approach memories that are otherwise too difficult to deal with? What are the limits of research approaches? According to Jon Kabat-Zinn:

To remember, then, can be thought of as reconnecting with membership, with the set to which what one already knows belongs. That which we have forgotten is still here, somewhere within us. It is access to it that is temporarily veiled. What has been forgotten needs to renew its membership in consciousness (2013, p. 98).

What happens when a researcher tries to reclaim membership to a traumatic memory anew as a research exploration? By reinterpreting my memories academically, can I expect a new understanding to make it easier for me to deal with my painful past in order that I can live my life more unperturbed today and in the future? Should I expect to be able to say, “Oh well, that was not as bad as I thought, after all”? I suppose not. This direction is simply to distance and reduce the significance of one’s memory, occupied in a personal history, which is neither good for the researcher nor for the private person. Jon Kabat-Zinn too reminds people to be careful about seeking a causal explanation for the memory. He reminds us that people cannot always know what happened in the past. The causal explanations may reduce the complexity of human experience. Jon Kabat-Zinn guides people to cultivate acceptance, by changing their relationship to past experience. He says it is a process of coming to terms with something. For Jon Kabat-Zinn, the difficult memory is something to let be by treating it and yourself mindfully. It is not something to chase after; rather one should let it come and go.

If recognising one’s own inner resources is the first step to cultivating a mindful approach towards a difficult past, which inner resources do I have to cultivate the patience and courage to come to terms with my past? At first I found it difficult to find any resources related to my cancer experiences as they all seemed too painful. However, when I dared to gradually look at the pain inside, I realised that inner resources can also be those that seem to be weaknesses. For me, one such inner resource and potential weakness was my anxiety. The hallmark of anxiety is avoidance or procrastination. But it can also be a signal that I am on the right track towards my past.

I have found that anxiety can be my research assistant by telling me where I would like to avoid going. It tells me the direction accurately by providing unpleasant bodily sensations. Although my body goes into a “fight or flight” mode, I try to mindfully approach what I do not want to approach in order to go beyond. And I will head in the direction anxiety tells me not to go. This has worked well so far. However, I also wonder if I can really trust my anxiety when dealing with traumatic memories. For

instance, a chronic procrastinator could spend the rest of his life procrastinating in order not to do the things that discomfort him. He can come up with as many excuses as he wants and as his creativity allows. In other words, my concern is that without enough awareness I may pick the easier path in order to avoid uncomfortable matters that are perhaps too stressful for me to deal with in writing the thesis. I am afraid that the method I choose can lead me into a maze made by my own creativity and survival instinct. If so, I would be fooling myself in trying to avoid more serious matters. This being said, I also notice that these sorts of questions can, in themselves, be an expression of my procrastination. Perhaps then, what I should do now is get started, step by step. “Take it as it comes” is certainly a mindful approach to anxiety.

When I take a mindful approach to my auto-ethnographic journey, I start to see the trajectory of change I have experienced over 13 years. I moved from being “the silent sufferer” (see Chapter 1), to “the wounded storyteller” (Frank 1995) (see Chapters 1 and 2). On my way for the second time to the world of cancer in Japan, I met my mentor Paul Stoller, who for some time had been living a life in remission in the world between health and sickness. I learned from him that people diagnosed with cancer wear a mask, what I call the cancer mask. Later I realised that patients’ families and bereaved families also wear the mask. In order to meet the faces behind the masks, I had to take the path towards being an attentive listener, especially when meeting family or bereaved family of cancer patients (see Chapter 4 and 5). What I have learnt is that telling one’s own story is difficult. However, listening attentively to sensitive matters and empathically responding to them in a sensitive way is even more difficult in a setting such as a support group for families and bereaved families. For example, in Japan, there is a strong norm to be sensitive to the stories of each other. My male protagonist in the film *To the Last Drop* (2016) was not eager to talk, although I quickly sensed that in reality it looked as though he wished to talk about what it was he hid deep inside himself. How should I approach him, balancing both the sorrow and fear he was feeling with Japanese communication codes? What would be the correct and most sensitive way to meet him? I kept asking myself this question, and also adjusted myself in the fieldwork. I started with the aim of making a collaborative project with my informants using visual media. I



had to learn how to be an attentive listener to sensitive matters, especially in the context of visual anthropology which has a strong focus on looking attentively instead of just seeing (MacDougall, 2005). I found that by using a mobile phone (see Chapter 4) I was able to be more aware of my bodily sense of listening, and how this listening attitude was perceived by those being filmed. I believe that a visual ethnographer has to show that he or she is listening attentively. But how? These are the issues this thesis will explore. In Chapter 6, my journey takes an interesting twist. Here I incorporate an amendment based on the dialogue about my thesis with my examiners. They helped me to see where I could delve deeper. I will first explore what it means to look at life with the cancer mask in light of a specific cultural context. Furthermore, I will discuss how my well-being, attentive listening, silence, and how my filmmaking approach has been shaped, both by my cancer experience and my Japanese cultural background. Here the notion of a space in-between, *ma* in Japanese, is explored through the issue of visual representation. I will also reflect upon the fruitful combination of auto-ethnographic writing and observational filmmaking. Lastly in Chapter 7, with my concluding remarks, I unfold my recent life situation to show that my journey is still taking place. I am living with ongoing health-related worries, although today I am more aware of the ways to handle it.

During the writing of my PhD project proposal, *Japanese cancer stories* (2012), I, like my colleagues, worked hard to write a well-polished opening paragraph, to invite my readers into the worlds of cancer as well as into my theoretical interests and methods:

The moment an individual is diagnosed with cancer, a new and different chapter in life is started; a chapter that asks people confronting cancer and those close to them, their “zone of trust”, to learn a new way of being and communicating in order for both to cope with the illness condition and anticipate the future. *Japanese Cancer Stories* explores the patients and how their zones of trust re-establish continuity in their everyday lives in Japan, and more specifically how they use empathy to emotionally communicate sensitive topics and issues that are difficult to put into words. Empathy, our affective and imaginative capacity, is one way of attending to what is not said. The project draws on knowledge from the anthropological field of communication. It aims to contribute to an increased understanding of

the social and existential limitations and possibilities found in communication, in particular pertaining to Japan. Building on empathy as a process of creating mutual influence on each other, the project seeks to establish a shared understanding between the researcher and participants by setting a common research goal for the investigation. This will further build on and demonstrate the production of knowledge that goes on between them. It will ask participants to present their lived experience through visual media. In this visual collaborative project, they will film, edit, and disseminate their stories to their zone of trust, and the zone of trust and the researcher will be given the possibility to do the same in response (taken from Wake's PhD proposal (Wake, p. 3)).

When I read it today, a few years later, I still feel that it is well written, though it makes me wonder why I thought people afflicted by cancer in Japan would have time to make a mini-film project to express their lived experiences. I should have thought carefully, what if I had been asked to make such a mini-film? I would not have done that myself. Why would I want to make a film about my deepest fear because someone is interested in it as a research project? More importantly, why did I believe that people would have time, when they were already busy with their lives, family, work, and hospitals? I see that I was influenced by the current anthropological trend in collaborative ethnography. I was also, based on my previous film, *Ippo Ippo* (2010), invited to film festivals, and here I got to see how collaborative film projects were presented. The trend is to set a common goal, and to produce a shared result. But in doing so, *whose story is it?* Is it a collaborative project or a way of recruiting research participants while navigating them into telling their stories in the way the researcher wants?

During the fieldwork, I had to make a major adjustment from planning to be someone who initiated a collaborative project to participating collaboratively in their daily interests. I will explore this more deeply in Chapter 4 when I invite the readers to watch my film, *To the Last Drop* (2016), which is part of the thesis. The film is not just additional material for the thesis, but co-expresses alongside the written text so that the two parts are mutually enhanced, both in the descriptions, complexity and sensitivity that cancer brings to the lives of people. This takes place in a way that each

part alone would not be able to do. This thesis captures the silence we find in the film, while the film is able to express the silence that is difficult to put down in words.

Before moving on, I have to underline another critical remark about my project proposal. It relates to the way I wrote the following sentence, repeated below:

The moment an individual is diagnosed with cancer a new and different chapter in life is started, a chapter that asks people confronting cancer and those close to them, their “zone of trust”, to learn a new way of being and communicating in order for both to cope with the illness condition and anticipate the future.

When I look at it again, I see that in the research process I made my own experience into a theoretical abstraction. I feel angry with myself for describing such life-changing moments in an academic jargon, completely detached from all emotional dimensions that still so deeply affect me 13 years after my cancer journey started. Quite simply, life was not like that. The challenge was not simply to cope with the illness together with those around me. In fact, when I was given my first cancer diagnosis, it was much messier and overwhelmingly awful, and I did not feel in harmony with my own zone of trust.

This is how my story goes:

# 1. Chapter One

## 1.1 First Cancer Diagnosis in the US

“Do you remember if you were bitten by a spider?” My GP in the US asked me after he had examined the swollen lymph node on my neck. He said it could be either “a spider bite or possibly also a type of cancer”. I was very puzzled and shocked by the news. I was certain I had not been bitten by a spider. But had I? Even though I already knew the answer, I was searching my memory to see if there was something I could recall. But why? It could not be true. I was too young for a serious illness like cancer. I was only twenty-four. When growing up in Japan, I never met anyone with cancer. What I knew was that cancer was a deadly disease, and that it was only supposed to happen to old or extremely unfortunate people. Actually, I only knew cancer through the masterpiece of a film by Kurosawa, *Ikiru* (生きる, *To Live*, 1952).

The protagonist is a late middle-aged man who dies from cancer at the end of the film. My knowledge about cancer at the time in 2004 was the same as it had been in the 1950s in Japan. The film was based on the premise that cancer had no cure, so being diagnosed with cancer was synonymous to a “death sentence” (Ohnuki-Tierny, 1984; Kakai, 2002). Indeed, since the early 80’s, it has been the number one cause of death (Ministry of Health, Labour and Welfare, 2017<sup>1</sup>). Yet, I knew vaguely that cancer treatment had been improved so that being diagnosed with cancer did not mean one would die quickly, but it would be even more terrible since cancer patients had to go through a slow death with tremendous pain as a result of the harsh treatments of surgery, chemotherapy, and operation. I had no idea how one would cope with the burden of and suffering from harsh cancer treatments, and if one was lucky and somehow survived, then how one would live a life afterwards with all the physical, emotional, and spiritual wounds?

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<sup>1</sup> <http://www.mhlw.go.jp/toukei/saikin/hw/jinkou/geppo/nengai15/dl/gaikyou27.pdf>

My GP asked me if I was comfortable with letting his trainee touch my neck. The trainee was as young as I was, and seemed nervous. With my permission, the trainee approached me. For a moment, our eyes met. This was awkward eye contact for me, and probably for him also, as I saw his cheeks blush. He did not say anything to me, simply followed his instructions from the GP. I did not know what they were talking about most of the time because then I had quite limited skills in English. Only a year earlier, when I arrived in the US, my English was considered to be beginner's level at an ESL school (English as a Second Language). I was mostly trying to concentrate on reading their body language to support my listening skills. And indeed, through the physical sensation of the touch, I could tell that the GP was making sure the trainee touched it right so that he would feel the lump in my neck, which I had obsessively been touching myself during the past few months as it grew, and as I was getting more worried.

It was not a spider, after all. My oncologist gave me a cancer diagnosis based on the results of the biopsy. My worst nightmare came true. For days, I went through all sorts of negative emotions. I did not know how to make sense of the situation, and I did not know how to pull through, if that was possible at all. Being in this chaotic situation made me feel as though everything was against me. I cursed my destiny and felt anger because of the unfairness. It made me even angrier to recall the trainee's nervous look. I was probably a good case study for him to gain experience as a medical student. He could learn how to examine the cancerous lump on the neck of a patient who was as young as he was. His nervous look made me feel I was merely an object of study for him through which he could gain real life experience and knowledge the textbooks could not provide. His touch made me aware of our different life conditions - on one hand, a successful, elite student who is promised the life of a medical doctor. He would have a good income and probably make an important difference to the lives of others. He would save lives while I might lose mine. On the other hand, I was still working on my community college degree at this age. I felt I was old compared to my classmates who were still in their teens. My aim was to achieve an American college degree so that I might achieve something beyond the blue-collar jobs I had had in

Japan. Now I was not even sure I would be able to continue with my studies and my life. But I did not want to go back home to Japan to meet my family, without a degree, and without hope. I knew my grandparents, parents, and brothers had good faith in me, and I also reassured them that, this time, I would complete my education to make a difference to my life. They had been worried about my way of life since I was a teenager.

Indeed, my family was of great concern to me. Early on, I wondered whether I could go through this experience on my own. I recall that before my oncologist had given me the cancer diagnosis, I said to him something like, “My family is in Japan. So, they cannot come. I want you to tell me the result.” I was afraid he might not tell me the true diagnosis if it was cancer, especially to a young patient like me, and that he would suggest I brought in my family. If he did say that, I would know he was trying to hide the true diagnosis from me and instead tell them. Back then, I was not aware my way of thinking had been shaped by a time when the concealment of a cancer diagnosis was the ethical norm for a doctor in Japan. According to Sato et al.:

Prior to the early 1980s, cancer patients in Japan were generally not told of their diagnosis, as Japanese physicians deemed it unethical to reveal what they considered a “death sentence” and patients were also reluctant to know their true condition (2012, p. 26).

I am not sure whether these patients were reluctant, as this did not match with my own experience. But if it were the case, then I wonder if many of them were fortunate to be able to rely on their families, knowing they would receive support and reassurance. Personally, I was not reluctant. I was desperate to know the truth, like Watanabe, the propagandist of *Ikiru*. Watanabe tried to confront his doctor to receive the true diagnosis. He was given a tip from another patient: if the doctor told him he had a mild ulcer, and there was no need yet for an operation, nor was there any need for a change of diet, then the true diagnosis would be stomach cancer (and he could expect to have less than a year to live). As it turned out, that was exactly what the doctor told him, and so Watanabe knew the truth. Interestingly, even

though Watanabe strongly demands his doctor openly tells him the truth, the doctor persisted with his diagnosis (*Ikiru*, 1952. 00:12:25 – 00:18:09).



Figure 1: Screenshot of Kurosawa's film *Ikiru*, 1952.

Figure 1 shows the intense moment of disruption in communication between the patient and the doctor - the doctor becomes aware that his patient seems to know the truth (as the patient insists the doctor tell him the truth rather than covering up the diagnosis), but the doctor continues to deny it. Why does the doctor refuse to openly talk to Watanabe? According to medical anthropologist and expert on Japan Susan Long:

Japanese physicians ardently feel that by revealing the diagnosis to a terminally ill patient, they will extinguish the patient's hope. If the patient has no hope, he will not 'fight to live' and in many cases may even commit suicide (1982, p. 2013).

By applying this interpretation on the scene, it looks as though the doctor is trying to instil hope in Watanabe. If Watanabe did not know the truth, then the doctor's hope

could assist him for some time until his cancer had taken away all of his physical strength and the doctor would not need to be concerned about the possibility of Watanabe committing suicide (he would be too weak by then). In this sense, instilling hope allows the doctor to not feel guilty about his impotence as a physician to save his patient. But since Watanabe knew the truth, the same gesture from the doctor was a very clear message to him that he refused to offer any emotional support.

The interaction between the doctor and Watanabe would be considered a prime example of “bad” communication as defined by communication experts and doctors in the field of oncology and health in Japan today. For instance, the oncologist’s bodily posture says something about his unfriendly attitude, and in fact, the image reminds me of one “bad” example in the Peer Support Programme from 2013 (see photo to the right in Figure 2).



Figure 2: Screenshot from the Cancer Peer Support DVD (Japanese Cancer Society, 2013). Examples of “Good” (Left) and “Bad” (Right) listening styles.

I will explore the program further in Section 5.3, but in brief, the Peer Support Programme is commissioned by the Ministry of Health, Labour and Welfare in Japan, and the program is designed by leading psycho-oncologists as well as leaders of NPOs



(Non-Profit Organizations) within the field of cancer (from the Cancer peer support textbook, Japanese Cancer Society, 2013, p. 11). During the time of my fieldwork in 2013, I had the chance to participate in a seminar which teaches good and bad communication. When I looked into the contributors of this programme, one of the psycho-oncologists was directly involved in the design of the Japanese SHARE programme (Tang et al., 2014), which is a model for oncologists on how to communicate well with their patients. I wish I could ask them if they had Kurosawa's film in mind when they made it, as the "bad" case looks very much like the scene in his film. For the "good" case, they recommend you "to sit relaxed on a chair and lean forward a little to give the impression that you are listening attentively" (ibid, p. 46). It says that controlling one's gaze, the timing of your nods and repetition of phrases, together with sitting in the correct posture, are a basis for "creating an atmosphere of comfortable speaking." The textbook explains the reasons for sitting in this way<sup>2</sup>:

When having a one-to-one talk, it is known that sitting face to face can make the other person nervous... by moving the chair slightly and changing its position, when you look at each other diagonally, then both can talk in a relaxed way. If it is not possible to move the table and chairs, using the corner of the table can work (ibid, p. 45).

When I consider the role of the body during a clinical encounter, I found that Watanabe's doctor almost seemed to forget the following fact: human communication is more than just an exchange of words. In fact, his own body tells its own story; the gaze, facial expressions, gestures, and bodily posture all very clearly communicate his rejection and antipathy towards his patient.

My American oncologist, however, showed quite a different attitude towards me. He did not seem to mind that I was not with my family during the clinical consultation, and he rather frankly, yet sympathetically, told me the cancer diagnosis. I did not know that open disclosure of the diagnosis had been the general approach in the US for quite some time. According to DeVecchio Good et al.:

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<sup>2</sup> All translations from the Peer Support Textbook by Shotaro Wake.

A generation ago, American physicians seldom told patients the diagnosis of cancer; today, there is virtual unanimity in our country on the ethical and legal obligation to disclose the diagnosis (1990, p. 59).

By reflecting on the episode today, I see that my strategy of forcing the truth from the oncologist turned out to be an unnecessary effort, as well as having little accuracy in context of their way of communicating with patients in the US. My strategy was rooted in the idea that the doctor often secretly discloses to a patient's family first, before together deciding if they should tell the patient or not, for the sake of reducing the patient's burden (Akabayashi, Fetters and Elwyn, 1999, Kakai, 2002). This is just the first example of cross-cultural communication difficulties with my American oncologist.

## *1.2 A Dose of Hope and my Effort to Overcome Cancer Stigma*

DeIVecchio Good and her colleagues (1990) show that the ethical attitude of American oncologists towards their patients is about “controlling information [which] is essential to maintain or instil an optimistic attitude in their patients” (p. 75). With this in mind, I recall that my oncologist presented me with a “good” scenario that certainly motivated me to be optimistic and hopeful. What he told me was that I could continue with my studies while undergoing cancer treatment. I was delighted to hear this, and uplifted from my feelings of despair. It raised the hope that I could perhaps keep things normal, the way they used to be, including the idea that I might not have to tell my family this terrible news. Why would they have to know if my cancer is an easy kind to treat? I did not want to make my family in Japan worry if it was unnecessary. I hated to think my mother would go about her daily life in tears and worry. That would double my concern. Of course, this route would mean I would not receive any emotional help from my family, only from my oncologist and maybe from those working at his office. But, again, why not? I had already had the positive impression that my oncologist seemed to be a person who would kindly listen to me if I had any questions regarding my health and treatment. So, I secretly decided to keep things quiet from my family and friends in Japan. As simple as that. It sounded like a nice idea, though at the time I was unaware that I was underestimating what it meant to take care of the emotional burden that comes with cancer alone.

What I see here is that I seemed to be improvising alongside my oncologist’s scenario of moving my cancer journey in a personal direction, by going away from the traditional Japanese cultural norm of dealing with cancer as a family project. No wonder my cancer journey ended up looking like Watanabe’s, although our relationships with our respective families were quite different. In Watanabe’s case, he could not tell his family because he sensed that his son and daughter-in-law would probably find it bothersome to take care of him. In my case, I did not tell my family

because I hated the idea that my illness might take away their hopes of my future after my education was finished. But unconsciously, I might also have wanted to do it my way because they may have redirected the scenario. For instance, they might have suggested that I go back to Japan. But what would I do, even if I survived, without an education from the US? It was this terrible scenario that discouraged me. So, both Watanabe and I tried to take our destinies into our own hands without letting our families know. Yet, we knew that we were going through a drastic transformation, though there was a crucial difference between us in the ways we expressed the changes we hoped to establish. In the case of Watanabe, since treatment was not available for him over 50 years ago, he knew his life was limited. So his hope was, perhaps, to be seen and recognised for his unspoken effort by those who knew him, to make a positive difference *after he passed away*. The treatment had, however, become available in my time, and I take my oncologist's scenario further in that I wanted to make a difference *through* my transformation.

But I still had another serious question to ask my oncologist regarding the scenario. Whether I could achieve it seemed totally dependent on what he said. I asked him, "But what about my hair?" What I wanted to know was if the side-effects from the treatment would make me lose my hair on my head and face (eyebrows and eyelashes), as I expected it would. This question, I later found out, was one of the most typical questions that people ask when they are diagnosed with cancer. I have repeatedly heard the same thing, both from people I met during my fieldwork in Japan and from what I have seen in the literature regarding cancer patients' experiences, Japanese or not. Losing one's hair reminds people that they are going through a physical transformation, but in addition it has a wider social consequence in that other people could also recognise that the person is receiving cancer treatment. In Goffman's term (1963), I was afraid to be stigmatised by showing that I had suddenly lost my hair. Goffman sees that stigma is a social attribute that "spoils" one's social identity. Usually people have multiple social roles (e.g. a student, a worker, a traveller), and they switch between their roles according to the situation. But Goffman points out that stigma fixates the multiple roles into only one role, and that role is highly discrediting in social situations. It would turn the stigmatised person into the so-called

Other. I was afraid that I would be seen and treated differently from the other students. Arthur Frank nicely highlighted what stigma does in a social situation:

Stigma, Goffman points out, is embarrassing, not just for the stigmatized person but for those who are confronted with the stigma and have to react to it. Thus the work of the stigmatized person is not only to avoid embarrassing himself by being out of control in situations where control is expected. The person must also avoid embarrassing others (1995, p. 31).

I did not want to be embarrassed by other students. I wanted to continue with student life as it was before I was diagnosed with cancer. I wanted people to see me as I was before. Luckily, my oncologist assured me that I would not lose my hair as my chemo was of a milder type. I was very pleased with his response, because it would make student life easier. In Goffman's terms (1963), the oncologist's reply suggested my stigmatised cancer status would likely be a *discreditable* one and not a *discredited* one. The difference between the two seems critical since the first is a kind where a person can hide the source of stigma from others, compared to the second one where everything is visible. I understood my cancer status could go either way. That itself gave me hope, because it meant that if I put in a great effort to hide it, then I may very well get away with it, and could continue with my school life as it used to be. In Goffman's terminology, this would be called "passing". I was afraid that losing my hair would make my cancer status a *discredited* one. The discredited stigma is especially discomfoting because it makes it difficult to "pass"; it makes it difficult to avoid embarrassment in social situations, both for the stigmatized person and those who interact with them. It denies the sense of agency in people's impression management. This is perhaps why Goffman (1963) starts one of his books with a powerful episode of discredited stigma, a girl without a nose. Imagine how many times a day she felt embarrassed and had to see the reactions of others whom were also embarrassed. Most of them would probably make their best efforts to try to hide their reactions from her. Some may think they managed it by keeping their reactions to a minimum. But for the girl, she must have enough experience to see what others see, and has acquired the skill of spotting their efforts even from subtle expressions

in their behaviours. She has become sensitive to what others try to do, and it constantly reminds her that she is a stigmatised subject.

In Watanabe's case, he does not know that his doctor talked behind his back after he left the office. But the audience watching the film knows, because they see that Watanabe is embarrassed by the way the chief doctor (who refused to tell him the truth) uses Watanabe as a textbook case for a young doctor, so that he can reflect on his own circumstances, and how fortunate he is to be young and healthy, unlike Watanabe. It scared me to think that other students would perceive me as different from them, in a negative sense. Even if I had the credible status of a good student, cancer would turn it into a dramatic one. I would be a good student with cancer (and probably one who is dying). That too sounded like a textbook case. Some might see me as a good reminder for them to reflect on their own lives and to cultivate their sense of appreciation for things that they take for granted, like health, time, and opportunities.

Thus, I was pleased with the idea that I had some agency to negotiate my impression upon others, or what Goffman (1959) famously termed "the impression management". I felt hopeful that if I performed well in acting like a healthy, normal person, I might be able to continue to blend in among the other students. I was not as concerned about how to "pass" my parents, since they could not see me even if I lost my hair. Our communication medium back then was by international phone call, and it took a few more years before we started using video calls. However, in my daily life, I still had to go to school and meet other students and instructors. But although I might be able to hide my lack of hair by wearing a wig or a knit cap, I would not know how to hide the fact that I did not have eyebrows or eyelashes. Wearing make-up was not an option since I did not have the skill to use it. I could imagine that if it were done poorly it would merely highlight the fact that I was trying to hide my signs of stigma. These were the type of thoughts I ruminated about, prior to treatment and before I had clarified with my oncologist that I most likely would not lose my hair.

Having a cancer within me was fearful, but it was still an abstract concept since I could not see it directly myself. However, the idea of being perceived as someone with cancer by other students was discomforting. Indeed, Goffman (1963, p. 138) writes, “the normal and the stigmatized are not persons but rather perspectives.” What I was particularly afraid of was not how I communicated with others if they knew about my cancer, as I was not interested in talking about it with them, but I was afraid they might express certain reactions that could perhaps reveal knowledge about my health condition that I could not see. For instance, they might easily know from my appearance and behaviour that I was not well. Since change is gradual, it is often more difficult to spot one’s own physical changes by looking in the mirror, while others have the benefit of time intervals. They can compare your present appearance with what you looked like last time you met. “Oh, you’ve lost weight”, would remind me of the changes brought on by cancer. So, people who would only occasionally see me would find it easier to spot my declining health through changes in my appearance. And, I would know that simply from seeing their reaction. Their expressions could become omens, good or bad. It all came down to the simple, yet desirable idea that having a discreditable stigma could give me more options to perform well in social settings. In addition, of course, I also became very skilled at making interpretations that confirmed the people around me saw me as sick, while later on, however, I understood this was not always the case.

When I think about it, Watanabe also had a discreditable stigma in his social world, as he did not receive cancer treatment. He could go on normally with his life for some time, until he could no longer bear the pain. Kurosawa only showed Watanabe’s first encounter with the doctor. The director omitted the decline of Watanabe’s health. Kurosawa simply used the deadly disease to cause a dramatic change in the behaviour of the character and was not interested in exploring the process of Watanabe’s illness. Kurosawa most likely did not foresee that later generations of filmmakers would continue to imitate his use of cancer as a convenient device in shaping narrative. In addition, these filmmakers would continue to shape the negative view of cancer in Japan, which I will discuss in a later chapter. For now, what I can say is that Kurosawa had a special interest in the phase of passing, how Watanabe makes a positive change

in his life after he gets to know about his cancer, without letting others know. His secret contribution to society was known only after he died. Kurosawa inspires me to think that passing is itself an expression of one's own effort, endurance, and virtue in the traditional Japanese sense.

So, to sustain this multifaceted hope (for myself and for my family), the best strategy for me seemed to be to pretend to be normal in social situations, just like Watanabe did in his film. In other words, I preferred to "bear the burden of acting" to hide my stigma (Jain, 2013, p.85) rather than being perceived as someone who was embarrassing both to himself and to others. In this view, it can be said that both Watanabe and I chose to take on a complex role in the world of the healthy. In the case of Watanabe, he acted as a section manager at a city office *with a stomach issue* (like many can have). In my case, I was a student *who was not feeling well*. That was a more desirable role to play compared to being a Japanese student with cancer or even worse, a dying Japanese student. This is a complex role compared to Talcott Parsons's famous Sick role (Parsons, 2013 [1951]) in which the person's illness condition remains open to those who are around them, so the person with the sick role can feel free to express that he or she is not feeling well.

However, although we did not feel well, both Watanabe and I needed to pretend that we were feeling well ("I am fine, thank you!"). It meant that though we might be able to avoid embarrassment, we would also reject any possibility of help or support from others. It was a cost I had to pay to be a good actor. At this point in time, as mentioned, I did not know that the burden of keeping such emotionally sensitive matters to myself was so tough, just as Watanabe experienced in the film. In fact, Watanabe twice attempts to go upstairs in his house where his son is, perhaps with the intention of disclosing to him that he is dying, but he only ever makes it to the middle of the stairs. (*Ikiru*, 1952, 00:22:27 – 00:30:03). In my case, whenever I phoned my parents, I always had to say how well things were going at school, even when I was lying down in bed, bearing the pain from neck surgery and worrying about how I would prepare food or do household things. I only told them episodes of my daily life that sounded positive, though in reality the negative part was what mattered for me.



In terms of my school life, passing in all situations turned out to be almost impossible. Or, it seemed to be an unwise decision for me to pass certain people, such as some of the class instructors and administrators. Goffman would probably say that my behaviour was nothing special, but:

A very widely employed strategy of the discreditable person to handle his risks by dividing the world into a large group to whom he tells nothing, and a small group to whom he tells all and upon whose help he then relies (1963, p. 117).

And indeed, I needed their help to continue my student life in as normal way as possible. From this perspective, it also made sense why my parents were not part of my small group, because my school life in America did not require any technical help from them on a daily basis.

I needed a lot of help, especially from the international administration office because they handled student insurance. International students did not need to see a documentary like *Sicko* (Moore, 2007) to understand the lack of universal care in America. As soon as one was admitted to a school, international students were repeatedly informed by the international office about their insurance situation. All students must have insurance, since people without insurance could easily go bankrupt due to the huge medical bills in the US. I had to make sure that the school insurance fully covered my needs. After all, my overall treatment cost was roughly the same as buying a brand-new Mercedes Benz. I found out that the person who handled insurance was a woman called Kathy, the international student officer. I set my mind to telling her only practical matters related to my cancer, and decided I would not tell her anything even if she asked me how I was feeling.

Kathy turned out to be a friendly elderly woman who willingly listened to my story. Usually people had difficulty following my English, but I did not experience that with Kathy, who was skilled at understanding students who spoke a second language poorly. I thought I managed quite well without becoming emotional and told her the

whole story. She told me she would help with my insurance, and at the end, she gave me a big hug. Coming from a country like Japan, this is an unusual experience, and I would not have liked it in an ordinary situation. But, being held by her somehow loosened up my defensive attitude, and I could not hold back my tears. She continued to hold me tight. It was actually a really nice feeling to receive care from somebody like her. She let me know she understood I was going through this serious situation alone. Again, it was a wise decision for me to let Kathy know since it turned out to be an emotional burden to deal with the school insurance officers. They often paid, but occasionally they sent me a bill stating they had only partially paid or rejected to pay altogether. “Oh, again!” I got frustrated and had to go to Kathy, and she would give them a call. I saw that even an experienced school officer such as herself got frustrated by the way they tried to reject a bill, even though all bills were related to the same treatment. In the end, they were all paid, so I did not understand why they kept bothering me with them while I was dealing with cancer and my school life.

Having an empathic experience with Kathy did not mean that I started to look for other people to tell my story to. I interpreted this as a rare experience, and that was as good as I could hope to get. Later during my fieldwork at the cancer support group, I found that this is typical behaviour amongst men. They tend to underestimate the need to talk. Some may give it a try, but even if they feel good afterwards, they would say, “Ok, I did it, so now there is nothing more to talk about”, as if their complex emotional experiences through a cancer journey could be summarised in one conversation. They seem not to have learnt how to talk about their emotions. The same remains the case for younger generations. I was repeatedly told by my father, my family, friends, and teachers of value that men should not express their emotions. “Don’t cry and complain, because you are a boy!”

Seeing this episode today, I wonder what my oncologist would think if he knew how I interpreted the way he presented my prognosis? I hope he would not think I negatively twisted it. My case shows that hope is not simply given as a one-sided action from oncologist to patient, like some American oncologists seem to think, as illustrated by the study of DelVecchio Good and her colleagues (1990). I, as a patient,

actively improvised and elaborated on the positive scenario in a way that suited my own needs. Thus, clinical hope may be better viewed as a collaborative project, and the oncologist may need to more actively consider the role of the patient in that process. I have noticed this tendency in medical articles, in which they tend to *only* talk about their own roles during the clinical encounter. This can be seen, for instance, in how they perceive empathy in this encounter. Although empathy is the human ability to imagine and feel the point of view of others, they reduced it into the core communication skill *for them* to get to know about the patient, while they seem to have little concern about what the patients do in the process. Anthropologists Douglas Hollan and Jason Throop (2008) especially discuss the role of “Others” in the empathic process. Hollan argues that:

It is well and good for anthropologists to think about how we attempt to empathize with others, but it might be even more important for us to know how others imagine or allow themselves to be known and understood (2008, p. 487).

He continues, “When and how do people allow themselves to be understood? When and how do they resist understanding by others?” (ibid, p. 487). This is a theme that repeatedly comes to play throughout my cancer journey, and which I will elaborate further throughout my thesis. Empathic understanding seems often to fail, but sometimes it works out, somehow.

Another interesting issue was that the hope instilled in me at the clinical encounter worked like a medicine specifically prescribed for me. With these doses of hope, I felt as though I could sustain my everyday life with a healthy mentality as my oncologist probably wished me to do - being optimistic and hopeful rather than desperate and hopeless. But at the same time, the effect of hope fades just like the effect of a medicine does. So, I had to continue to take “the medicine of hope” as I continued along on my cancer journey. Remembering the phrase of the oncologist, “an easy kind of cancer to treat” worked for me in the same way as taking a pill whenever I was worried and felt alone. It made me think that my condition was only temporary rather than permanent. I could believe there was a way out, although at the time it did not

feel like there was, and the idea was evoked simply by my oncologist's short sentence. He probably had no conscious awareness of how life changing this sentence was for me, as if we were both in a collaborative project of hope, which neither of us were aware of participating in. It is interesting to see now how important a few words can be; how they can instate a certain emotion in a positive or negative way, and how one's timeline can change direction just like that. Thus, with a positive prognosis and a dose of hope from my American oncologist, I felt less frightened when departing on my cancer journey. I had a vision (the treatment plan) and a good prospect ("easy to treat"), so what I wanted to know was how to go about it. Or even, how I could go about it *well* on my cancer journey.

### ***1.3 Passing through Everyday Life with a Cancer Hero Mentality***

Lance Armstrong was my role model at the time of my cancer treatment in the US. Today we know that he has been divested of many of his titles as a professional cyclist, including his seven victories in the *Tour de France*. However, back then I did not know, and nobody seemed to know that his hero story was “one big lie”, as Armstrong himself later admitted (Oprah Winfrey Show, Lance Armstrong’s Confession, 2013). Without knowing the truth behind his performance, Armstrong seemed to be a better role model to me than Watanabe. Perhaps, for me, the most crucial difference between the two is that Armstrong survives from cancer and continues to live while Watanabe dies in the end. In this line of thinking, like Watanabe, Armstrong too made a tremendous difference in his career and life after being diagnosed with cancer. Even more, he did not just survive it, but became better, stronger, and healthier! If the oncologist showed me a horizon of hope, and provided me with a vision for my road map, then Armstrong showed me how my hopes could come true. I learnt to be a cancer survivor like Armstrong where you define your own challenge, work hard to conquer it, seek the next challenge and so on and so forth. However, I also learnt that it comes at the cost of being able to maintain this high performance throughout my cancer journey.

Sometime after being diagnosed with cancer, I bought a copy of Lance Armstrong’s cancer autobiography, *It’s Not About the Bike: My Journey Back to Life* (2001). The book was one of the top 10 best-selling books and I saw copies were piled up high in almost every bookshop. At the time, I did not know anything about Armstrong, but I remember I came across the word “cancer”, not in the book but on a note that booksellers add when they display the books. The short description helped me to see that the guy on the cover had cancer, but was doing well today. I did not understand the technical term for the kind of cancer he had, but I learnt that he survived even though it had spread to his brain. It looked like a miracle to me, especially since I did

not find any trace of illness or sense of pain and suffering on the book cover. He looked quite at ease, peaceful, and athletic. I also learnt that a person like him is called a cancer survivor. This was it! This book would be my “desert-island book”, the one I wanted to bring along on my cancer journey. I wanted to know his story, and maybe I would find some helpful hints. But again, what reassured me the most was the simple fact that there was a man out there who had survived a worse type of cancer and worse conditions than the ones I had been diagnosed with. If he could do it, why couldn't I? I found a new hope I could cling onto. I was not critical about the promise in the book that everybody with cancer could survive, just like Armstrong, if they only worked hard for it. According to Sarah Lochlann Jain (2013), the author of *Malignant*, what Armstrong tried to sell was “a comforting ideal of survivorship” (p. 55):

In Armstrong, age, class, gender, and a curable cancer along with his brilliantly choreographed cheating, masochistic training schedule, and dazzling marketing skill combined to form an icon of cancer survivorship. His status overshadows a simple fact: cancer can completely destroy your finances and your family's future (ibid, p. 58).

Jain helps me to see today that I could uncritically buy into Armstrong's fairy tale because, fortunately, I was financially covered the school insurance. However, in another way of thinking, I have been looking for a role model to teach me how to increase my sense of personal power in taking control of my cancer journey. Like Watanabe, a strategy for being a dependent patient would not work very well if one were unable to rely on his or her family, or on health experts. My oncologist was a supportive person, but I did not see him on a daily basis, I only saw him when I had appointments, so I was mostly on my own in my everyday life. But it was too scary for me if all I could do was sit and wait for the treatment to take effect. I wanted to do something, though I did not know what I could do to increase the chances of survival.

But what did I learn from the book other than background information about Armstrong? I do not remember anything specific. What I remember is the fact that just having the book and flipping through a few pages here and there made me feel good, it filled me with courage, hope, and energy. Maybe I was not able to fully follow

the plot of the story with my poor ability to read English. And/or I was not really interested in the details of his story. The main message of the book was what mattered to me, like the one I was given by my oncologist. The book also provided me with a simple and easy message, not necessarily because it was skilfully created, but it did not deal with the serious issues Sarah Jain (2007) and other scholars with cancer try to deal with. The book only deals with what Jain calls the public face of cancer culture, such as cure, hope, and survival figures. The book did not include “[t]he private face of cancer cultures – grief, anger, death, and loss [...]” (ibid, pp. 89-90). However, when I read the book again, I see that it also includes emotionally sensitive matters like his encounters with the issue of money, love, losing and gaining his physical strength again, and his bike injury. But in one way, they are all just episodes that help make the narrative more interesting and dramatic for the audience and guide them in the direction of the goal, where he achieves his survival victory. I already knew this before reading his book (see Figure 3 below).

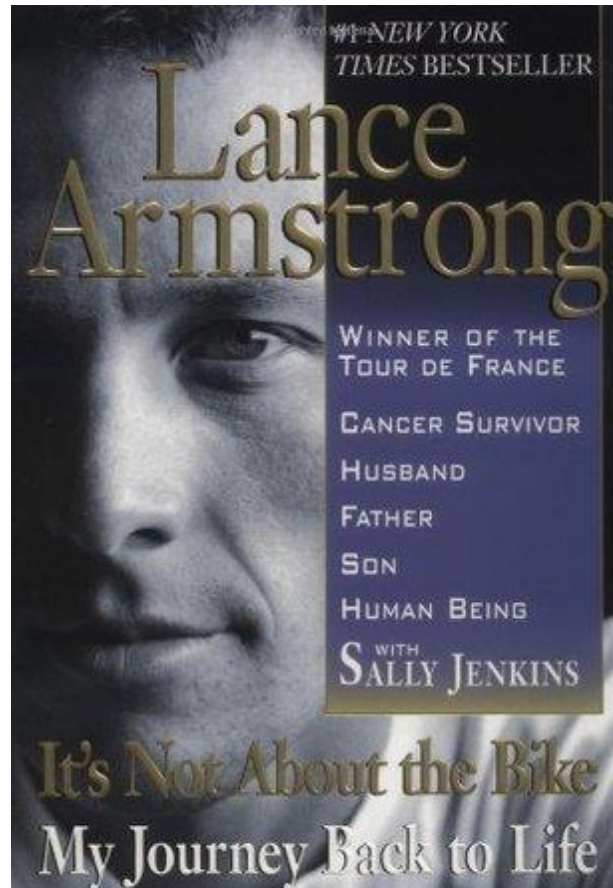


Figure 3: The cover of the book *It's Not About the Bike: My Journey Back to Life*, 2001.

The visual presentation of the cover tells the same story. The main message is shown visually by how good he looks today, even though he had cancer. He writes as a concluding remark, in the last paragraph of the book:

I'll spend the rest of my life puzzling over my survival. Cancer no longer consumes my life, my thoughts or my behaviour, but the changes it wrought are there in me unalterable (2001, p. 288).

He suggests that cancer is a past event, and today, in 2001, he is at ease after having had a long journey. Reading this book today, after ten years of worrying about my cancer, being fully consumed by it, and having met others who also struggle like I do in my fieldwork, I do not buy that he no longer has concerns related to cancer, especially the possibility of relapse. But the cover photo denies any such interpretation. What the picture shows is that things have all gone back to normal; his hair has grown back, no sense of fatigue, and everything seems at peace. Of course, as a marketing



strategy, he was unable to show any sign of weakness or sickness to his customers. What Armstrong tries to sell, and what attracted me as a consumer, is the extremely seductive idea that a cancer patient can achieve something greater after their cancer treatment. Or the suggestion that cancer can give its sufferer a possibility for change to produce something greater. Armstrong's photo is a good example of "Looking as good as ever", something which is widely observed, for instance, among Hollywood celebrities. Consider publication events for new films where the Hollywood stars appear in the media trying to look their best to impress the public. They win when they can manipulate their image so that they look great despite any unhappy conditions or events, such as growing older, drug addiction, divorce, being broke, etc. In the same manner, Armstrong's survival story is not just a cancer survival story, but he achieved something greater from cancer within the health category.

I argue that the story of achieving something greater from a person's misery has a similar function as the role of the conjunction between clauses. For instance, the key idea of the book can be formalised into one statement: "I had cancer, but I am as strong as ever". The first clause is simply a negative statement, but written in the past tense. The reader knows that the author is talking from a different perspective, i.e. when he had cancer, and they can tell he is still alive today (at least until the time of publication). The performance of the conjunction "but" works actively to shift the negative in the first phrase in a positive direction. It is well known that in Logic, a negative times a negative makes a positive. The conjunction shows the difference between the two clauses by performing a contradiction. The conjunction helps to navigate the readers into a different space, from negative to positive, and the movement between the two spaces are interesting for those who follow the clauses. For instance, the dramatic effect is reduced if I replace the "but" with "and" ("I had cancer, and I am as strong as ever"). It is not as interesting and attractive as before. It does not sell. My assumption is that the "and" only provides a horizontal movement while "but" provides an upward spiral in this context. I assume "the inspirational story" is indeed nourished through the upward spiral. My assumption is that as the horizontal gap between the clauses is wider, the dramatic effect of the upward spiral comes out stronger.

In Armstrong's book, the highest peak of the story after cancer is his victory in the *Tour de France 2000*. This title, Winner of Tour de France, is supposed to go only to the best among all the world-class athletes. Nobody would have expected that a person who had experienced cancer could achieve such a victory seven times. Today we know that he used a performance-enhancing drug to make his American dream come true, but at the time, it looked as though he had flipped the world of healthy and sick upside down through recovery from cancer. He gave me the hope that I too could secretly transform myself to achieve something greater, as a sort of positive rebirth, during my cancer treatment. Armstrong offered an ideal which Watanabe could not. Armstrong made his dream come true, and the public admired him. He became the symbol of the American dream, a hero fighting an adversary called cancer. More importantly his book seemed to offer the idea that other people also can have their American dream and make it come true.

The nice thing is that Armstrong did not seem to ask complex things to achieve something greater. It appeared reasonable and achievable for someone like me. It seemed as though anyone with cancer could achieve what he had asked for. That implies, according to Sarah Jain (2013, p.55), having a "focused determination and responsibility for one's own future"; to stand up and fight the challenge. But what is the challenge? Armstrong would say that is up to each person. I see today that this is the core of Armstrong's message, let his consumers create their own challenges in whatever way is suitable for them. Setting up my own challenge, to fight it, was something I felt I could do, and probably something everybody could do. I could not fight cancer itself since it was in my body, but I could fight the challenge that I was faced with. That was a much easier target to aim for.

In my case, I decided to join the gym and trained hard, just like Armstrong. The physical challenge was a tempting and reasonable target. The challenge was something tangible, I could make my body stronger, and after doing some exercises I felt great. Think about it, the American hero starts his transformation in the gym. The perfect example is *Rocky* (Avildsen, Chartoff, and Winkler, 1976). With my skinny

body type, I felt intimidated showing up at the gym, amidst all those big guys who were working out with their heavy weights and drinking protein juice. Soon I bought myself not one bottle but a basket full of something which contained roughly 100 per cent Whey protein. Although I never ended up looking like them, it made me feel good to train because it gave me a sense of being under way, based on the ideal of “bigger is better”. It gave me a good feeling to build physical strength and stamina in order to resist side effects like fatigue, lack of energy, nausea, and pain. This strategy was not necessarily negative, even by today’s standard. More research shows positive and long lasting advantages from physical activity, both during and after the treatment (for instance, see Speck et al., 2010). However, I must say that my training was hardly comparable to Armstrong or any of the guys at the gym. My training method was not well formulated. The others working out probably thought that “the skinny Japanese man was just doing his thing.” Yet, I felt great and refreshed when I had finished my training programme and was on my way home. I felt like I was doing my share, just as Armstrong did.

Going to the gym had become a crucial daily routine during my radiation treatment. It was a hot summer, around the time of my 25<sup>th</sup> birthday, and I often came to the radiation office feeling fresh after running all the way from the gym. My T-shirt and shorts were sweaty from running. I guess no one at the gym ever imagined me as a cancer patient going to the radiation office afterwards. My positive performance seemed to work well. For instance, I recall a friendly woman at the reception desk in the radiation department who was always delighted to see me. She once told me, “You are my favourite patient”! When I asked her why, she told me it was because I always came in the office with a good spirit and looking joyful. So, I asked her, “Why shouldn’t I?” She then hesitated a little, lowered her voice to and told me something like, “You know, many of our patients are older people, and they often have more health problems.” I looked around the waiting room and realised what she meant. I was the only young patient. All the others were elderly and some of them clearly had physical difficulties. They sat quietly on their chairs, waiting for their call. I thought they looked worried and unhappy. That made me feel good, because I knew I was not like them. I was still young and strong. But I also noticed something in their look

when they saw me and realised that I was a young man. They tended to have a sorry look, and I also recognised a sense of relief in the expressions. They appeared to be relieved at the fact they had all lived a long life, something that this young man might not experience. Either way, there were no greetings between the patients at the radiation office other than the occasional and awkward meeting of eyes. The room was quiet with a sense of drama, and completely different from other social situations where Americans tend to casually greet each other and make small talk, be it at the bus stop, shops, gyms, or at school.

To the receptionist and those who knew me at the gym and school, I may have looked happy, but I was not feeling happy. I was working hard to act like a positive person. But when I was alone in my room, I simply could not take my mind away from thinking about my cancer and the treatment. Yes, I might have a good prognosis, but it was still scary and I could easily ruminate on being observed in some of the worst scenarios. “What if”, the typical expression provoking anxiety, had become my habitual thinking. Somehow, all I could come up with were the negative outcomes such as “What if the treatment does not work?”, and rarely the opposite: “What if everything is OK”? I was probably too scared to be alone.

Although I tried my best to resist the side effects of cancer treatment, it certainly started to work on me. I woke up every morning with a feeling of fatigue, and my body ached and felt heavy. This scared me, because it felt as though I was losing control. I tried to convince myself that it was just muscle pain from physical training. In some sense, deceiving myself helped me stop reflecting further on my condition. In front of people at school I had to pretend as if everything was all right. I struggled a bit with the gap between my positive performance and the negative emotions I felt, and with the gap between the sense of a normal life between me and other students. The worst thing was that no one knew how hard I was acting, and I did not know how long it had to go on. I woke up every morning disappointed it was still not over. A lot of effort was required to lift myself from bed. I had to pull myself through yet another day. This happened although it was probably the most ideal time for any cancer patient to be open since almost everybody on campus was wearing Lance Armstrong’s yellow

band. They could all have been my supporters. But I would not risk letting them know that I was a real cancer victim since I knew most of them were just following the trend. I did not seek another opportunity to talk with Kathy about my battle since I was also acting out the same positive attitude in front of her. Getting to the end of the treatment was all I was hoping for. That was the goal of my cancer journey, the moment when I crossed the finish line, which would surely lead me to experience the state in which, as Armstrong wrote (2001), “cancer no longer consumes my life, my thoughts or my behaviour”.

But the end of my cancer journey did not come as quickly as I wished. Even when the treatment had come to an end, I had already been booked for regular check-ups every three months with my oncologist. In these meetings, the oncologist stated that I was OK, and this reassured me, but only for some time. It diminished as the next meeting approached. I started to feel uneasy and worry, “What if I the cancer comes back?”. These thoughts were so powerful that I could ruminate on them all the time. I tried to reassure myself with the “easy to treat” chant. I was not sure if my fight was over, or if it was just a cease-fire. But either way, my positive and optimistic behaviour continued in everyday life, and it was exhausting to do that all the time with everybody.

Thinking back, performing as a positive and optimistic person has helped me to go through a certain phase in my cancer journey. But then, I wondered how long I would have to continue to set up my challenges and face them? Armstrong seemed to know how to motivate himself. As an athlete, he set his goals, one after the other, as they were met, as he won his victories. But again, as we know today, it was with help from performance-enhancing drugs. In fact, the doping did more than enhance his cycling abilities; it helped him to hide his weaknesses due to illness. So much about his true story represents American duality - strong and weak, positive and negative, talk and be silent, enable and disable (I can and I cannot). In this context, you are encouraged to talk openly about your struggle, and people would listen to you, as long as your story comes out positive in the end. To me, the case of Armstrong highlights how American culture also has its own communication difficulties around delicate topics related to one’s weaknesses. This does not only apply to Armstrong at all: consider

the US presidential campaign in 2016. For instance, Hillary Clinton's motto was "Stronger Together" (Clinton and Kaine, 2016). Some recall that Donald Trump repeatedly attacked her health. In one of his campaign adverts, it said: "Hillary Clinton doesn't have the fortitude, strength or stamina to lead in our world" (Time, 2016). Clinton faced up against such challenge by wearing a vivid red lipstick to help her look healthy and strong during the presidential debate. Clinton's post-election speech was a symbolic one because she showed up without wearing her make-up, admitting that the defeat made her feel like she wanted to withdraw from the public scene. Now she could show her weakness, because she had lost the battle. I struggled to keep up the ideal of acting positive and optimistic all the time, but I did not know what else to do. Watanabe also became restless. Maintaining this positive energy-consuming performance certainly made me exhausted and I even burnt out after a certain period of time.

## *1.4 Life after American Hope has Expired*

While I felt exhausted from being positive and optimistic as a way of “passing” in my everyday college life, it perhaps had a positive effect on my performance as a student. I was certainly motivated and determined to achieve my college degree with a good grade. I was most certainly a so-called serious student. Thus, I earned something greater than I initially expected. With my college degree, I could make a transfer to the University of California, Berkeley. To be honest, I did not know much about UC Berkeley when I applied. If I remember correctly, UC Berkeley was one of the universities in California which you could apply to in one single application. That I was accepted into Berkeley was a bit of a surprise among people I knew at my local college. Excited, they told me how big a deal it was for any student to be accepted at a prestigious university like UC Berkeley. Apparently, few students were going to transfer to a university from my local college in Seattle, and if they did, they tended to transfer to local universities. Only a few would go to a prestigious one in another state, and then even to California! They admired me for being able to say goodbye to a city where I felt like it was raining almost 365 days a year. For some I made an American dream in education come true. I felt proud when recognising their admiration, and I secretly celebrated the fact that I, as a former cancer patient, achieved something greater from my challenge, just like Armstrong did.

Today I feel embarrassed that I was proud only because of the name of the school, compared to those who have a clear objective and determination for what they want to do in their subject field. For me, it was probably just another challenge that I would like to face and conquer, again in the same way as Armstrong did. I was hoping that I could take yet another step away from the cancer world. But I was less aware of the fact that the next challenge also needed to be greater than the previous one. Would anyone take Armstrong seriously if he won seven times in a local bicycle race after his cancer? Although this would be a remarkable achievement for anyone who has experienced cancer, it is not big enough for people who seek both inspiration and entertainment, and a story with lots of drama. In my case, I had secretly decided that

I wanted to major in something that would otherwise not be possible if I were still in Japan. I believed studying film would be a certain way into the American movie industry. Back then, I did not know anything about how the American movie industry worked (I still do not). I did not know that I had ended up in a study programme as far away from the Hollywood film industry as I could get, since the programme had a strong tradition for the avant-garde and documentary film movements in San Francisco, and in addition was very critical of contemporary Hollywood films. They knew how to study film, but they knew very little about how the Hollywood industry worked, except for Mark Berger, the four time Oscar winner who taught me the remarkable world of understanding and constructing sound in cinema. I do not regret my choice, since my study programme certainly helped broaden my understanding about the world of cinema. Through studying theory, history, and watching film across many different genres, my bad taste in popular Hollywood and Japanese movies was washed away. I got to know the works of great filmmakers like Vittorio De Sica and Hitchcock, the Iranian filmmaker Kiarostami, Stanley Brakhage and Michael Snow in avant-garde, Jean Rouch and Robert Gardner in ethnographic films, and early Japanese filmmakers including Ozu, Naruse, and Mizoguchi.

Being a student at UC Berkeley was a new chapter in my life after cancer, and I was supposed to feel happier, especially since I could continue with my dream. Yet, I recall that there was almost an emptiness, a loss of motivation, in me. I suddenly lost the target for which I was fighting. I was standing on the UCB campus, watching people move in all directions, looking joyful in the sunny weather. Again, I felt the gap between me and other students, and I found it difficult to adjust to university life. I could also recognise my unhappiness from the way I engaged with my studies. I could talk passionately about film characters, such as Watanabe, who goes through various hardships in his life, while I did not tell anybody about the suffering I experienced through having cancer. Jain (2013, p. 55) argues that “[t]he Armstrong story comes with real social costs for many people surviving with and dying of cancer”. This was probably also the case for people like me, who, back then only knew Armstrong’s way of approaching cancer.



My unhappiness in Berkeley was related to the fact that I had started a new chapter in my life; a former cancer patient. I still had to meet an oncologist for regular check-ups. This was disappointing, because I could not conclude my cancer experience, like Armstrong wrote. That was the first time I was referred to individual counselling at the university health service. When I told the GP that I had gone through cancer alone, without my family even knowing about it, he advised me to see a counsellor. I remember I was not too keen, but did not reject it either. I had an awareness that things were not going as well as I had hoped. I think I told the counsellor something like “I am here because my doctor asked me to come. I don’t think I have anything to talk about”. But when the counsellor asked me a few questions regarding my cancer experience, I started to talk, and in fact I could not stop talking. I went on and on until the counsellor had to remind me that the time for the session had run out. But I felt like it was just the beginning, and the interesting story comes from this point on. Maybe I was excited because finally I had found a way to talk about my story, a story that no one knew, while secretly I had wished for someone who was willing to listen to me. I was amazed by how nice I felt. I agreed to meet the counsellor again, but also recall that later, when I was alone, I got scared, as if my story no longer belonged only to me. It did not take long until I had used up the maximum number of sessions I could use in that service. Therefore, I had to seek my own professional counsellor outside of campus who would be covered by my university insurance.

I recall that sometime after starting to talk to the university counsellor, I began to experience a feeling of fear in my daily life. I would suddenly get frightened, for instance, while walking on campus. I just did not see the connection between my feeling and the reason why I got scared so suddenly. It made me feel like I was going crazy. It was probably the first time that I started to worry, not about a cancer relapse, but about my mental health. I was no longer certain about myself. I did not know what would happen to me when I had finished my cancer treatment. I was emotionally upset, thinking, “I have to do something. I cannot go crazy now when I have no one to rely on”. My anxiety got stronger and stronger, to the extent that once or twice I experienced panic attacks. That made me even more desperate to seek counselling.

I was invited to the office of the first counsellor. She seemed like a nice elderly lady with long silver hair, and with clothes a mixture of hippie and yogi, which was quite normal in a city like Berkeley. Her office had a relaxing atmosphere. The flowers in their green pots were getting warm sunlight from the window. That made me a little at ease, although I was still nervous since I did not know how to go about it all, especially the fact I might have to tell her I was perhaps going crazy. At that point this sounded scarier than telling her that I had my cancer experiences. She invited me to sit and asked me what my preferred style of counselling was. I might have understood what she meant if I had read through her profile, where her therapeutic approach was described, before making the appointment. She said, "Would you like to draw?" She gave me pen and paper. Immediately I felt discomfort. Draw? I thought, "Why on earth would I have to draw something, like a child, when I am worried my whole world is about to collapse!" She seemed to sense that I was not too keen on the idea, so she took me to the balcony and encouraged me to blow a bubble. A bubble! I did not like this idea either. It was as if she was joking. But I did not dare be rude to her, so I blew the bubble anyway. Later, on the way back home after the session, I was frustrated by the fact the bubble stuff did not give me enough time to tell her the whole picture. I decided that I had to look for someone else who could be more serious than her. However, I can still remember the sense of a quiet moment when I was fully absorbed by the prism of colours shining through the bubbles floating in the air. I did not know that she had helped me to experience a so-called mindful moment.

My very first impression of the second counsellor was negative. The counsellor was a middle-aged man, looking rather untidy and non-athletic. He invited me into his tiny office. The only furniture was two old armchairs and a small table. He made himself comfortable by crossing his legs. He looked quite casual from the point of view of a Japanese man. I was sitting straight on my chair, and felt quite uncomfortable since I was sitting face-to-face with him in such a small room. The communication style clearly demonstrated a cultural clash between us. I wanted to leave, but I was not confident enough to negotiate cancelling our meeting, so I could do nothing but go through with the session. He kindly asked me to tell him anything I wanted to tell him, and asked me if it was OK that he took notes while listening to me. I said yes, but I

still was not sure that I could trust him. So I decided to tell him about my experiences related to cancer. The reason I told him about my cancer, which used to be a secret, was because I was not sure if I could tell him about my current concerns, which were my worrying thoughts. Despite my anticipation, the counsellor turned out to be a good listener. He let me go through a basic outline of my cancer experience patiently and co-operatively and he made me confident enough to disclose some of my worrying thoughts. I anxiously awaited his response while considering “What if he thinks I am crazy?”

The second counsellor glanced at the clock on the table, and gently told me that we did not have enough time to go through everything now, “But” he said, “I think I can help you”. I immediately felt relieved, and I got some hope, “He said he can help me!” My fragile path moving away from permanency to temporariness was immediately strengthened. This phrase felt so powerful, and it had a lasting impact on me. Through our sessions the counsellor taught me many things that would deepen my understanding about my inner world. He reminded me that I was not crazy, but was suffering from anxiety. He told me that the people whom I was referring to as “crazy people”, tended not to worry about their own sanity. They are quite certain about their own worldview, and instead, everybody else is wrong. Thus, my catastrophic feeling that the world was falling apart was an expression of a panic attack. He assured me that thinking one is about to go crazy is a typical anxiety response, something which comes in the form of a “What if” sentence. “What if I am going to go crazy, what if my heart suddenly stops beating, what if I get a stroke?” Such thoughts stimulate you into a sense of danger, putting you into the “fight or flight” mode where the blood pumps and the body is preparing to face the danger, while in reality, there is none.

He told me something remarkable that challenged my worldview. He told me that since I started to talk about my cancer with other people, I seemed to experience the negative feelings I had suppressed so hard at the time of my cancer treatment. I could not believe it because three years had already passed since the treatment. I learnt that these emotions tended to come back when a person is ready to feel. But I was not sure what he meant by “when I am ready”. He replied that a person is ready at the time

when things are more or less back to normal, and he has settled down. This is the time when he is doing well enough to deal with the suppressed feelings. To be honest, this idea sounded crazier than being afraid about my own sanity. I thought I could ignore my emotions, or pretend that they were not there until they went away, until my mood would change. Here I seemed to believe that emotions were something I could control if I put an effort in.

Taking perfect control was the hallmark of Armstrong's strategy towards his cancer and life. However, in his infamous TV interview, he confessed that while he tried hard to make and maintain his "mythic perfect story" (Oprah Winfrey Show, Lance Armstrong's Confession, 2013), he also felt as if he was beginning to lose control, and the public might find out about the truth. In my case, I also recall that I was frustrated by the idea that I could not get away from my worries. They seemed to come one after the other. Even after I was declared well, my feeling better and safe did not last very long, since somehow I found different ways to worry about my health. So, I became desperate to seek a state of suffering, free from my life with the Armstrong strategy. Today I know that this was an impossible goal, because suffering is part of the condition of human life.

Interestingly, when I became aware I was about to lose control over my sense of self, the possibility of seeking and receiving care from others became available. The counsellor also taught me that therapeutic effect comes through the act of talking so a person could let out his or her concerns, and this helps to create a distance from the experience. This was something completely new to me, of course, as it was not written in Armstrong's book. It took some time to accept the new worldview, and to understand my cancer experience. This episode was just the beginning of my counselling experience with different counsellors in different countries that eventually went on for years.

Thus, I see that the yogi-inspired counsellor's approach was not necessarily bad; maybe she helped me to relax so I could talk about my experiences. I did have a strong need to talk. I wanted to feel reassured and secure. I wanted to know, first and

foremost, that I would be all right, even before understanding anything about my struggle. This was also the case with the GP and his student. I felt like I was left behind while they were busy doing training. Kathy, the counsellor who said “I can help you”, and the oncologist, all reassured me from the very first encounter. Kathy minimised my concern over the medical bill, a source of serious worry that many Americans without insurance are facing, and although the oncologist gave me hope, there is a critical difference in the empathic approach between the counsellor and the oncologist. The counsellor gave me more than just reassurance by helping me to understand why I experienced the world the way I did.

I became more aware about the strangeness of my situation at the time of my cancer treatment in the US when I started to talk about my experiences with others (my Norwegian wife, who today is a psychologist, and people in the Japanese cancer support group). They wondered why my oncologist did not refer me to an emotional support service during the cancer treatment. They helped me to see that my treatment situation in the US could have been different. For instance, my wife asked me why the medical service could not provide me with a Japanese translator who could have enhanced the communication between doctor and patient. She thought this would have been especially helpful for a young man like me, going through a life-threatening disease, alone in a foreign country, and away from my family in Japan. Also, why was there no guidance for emotional support through cancer support groups? I recall how a woman in the cancer support group in Japan jokingly said to me, “Why were you left alone in the US? I thought they were advanced when it comes to (emotional and spiritual) support?” She seemed to be right. In the end, I discovered that according to the handbook for people with cancer written by a leading psycho-oncologist in Japan, I had almost all the “risk factors for developing adjustment disorder and depression”. Such factors include the patient being “young”, “living alone”, “in pain”, “of reduced physical strength”, “with nervous personality” and “having trouble receiving emotional care from those close to him”. The only thing that did not fit while I was living in the United States was “progressive or relapsed cancer” (Japanese Cancer Society, 2013, p. 24). Why was I not offered any emotional support alongside the consultations with my oncologist?

Thus, as I have reflected on my time in the US, I seemed to have both benefits and drawbacks by taking on the role of an American cancer hero, and by consuming the doses of hope from my American oncologist. On the one hand, being positive certainly gave me a lot of energy to keep going during a frantic time. However, my positive performance also deprived me of emotional support from medical professionals as well as from those around me. The implication of this was that I stopped the important flow of empathy that Hollan (2008) discusses, as I kept silent about my condition to everyone close to me. Although I strongly sought empathy, I effectively stopped it by not letting myself be empathised with. In addition, this made it difficult for others to be my supporter.

## *2. Chapter Two*

### *2.1 Second Diagnosis*

I received my second cancer diagnosis in Norway in 2010. It was some time after coming back from my first fieldwork with Ippo Ippo in Japan. I participated as a researcher, but I also became their newest cancer member. I was busy writing up the thesis and editing the film for my master's degree in Visual Cultural Studies at the University of Tromsø.

Receiving the second diagnosis was for me different from the first. There was a strong sense of anticipation, as though my worst nightmare was coming true. I had feared it might be back one day. But, at the same time, I also secretly had a hope that I could get away with it, since I was about to cross the five-year line since my first treatment in the US. Five years is a special period for many cancer patients, myself included. The survival rate is often charted in terms of a five-year span or a ten-year span. This idea is present in the work of Jackie Stacey when she reflects on her own cancer experience:

I am much more fortunate than many, in so far as there is a five-year threshold for teratoma patients, the crossing of which at least promises the all-clear. I am still subject to annual tests, but I am told that I am on much safer ground these days (1997, p. 7).

I was also secretly hoping that I could enter this safe zone, but I saw the gate closing right in front me. That was what it felt like. It reminded me of Nishi-san. She was one of the few members of Ippo Ippo who had survived second-time cancer treatment. She reminded others of how the second time is a completely different deal of, in her own terms, “being closer to the edge of the cliff”. She then got bad news yet again, only a month after we had toasted with non-alcoholic drinks to her five-year anniversary after her last treatment. “I fell down at the five-year mark...” she said to us with a

tight facial expression. No one seemed to know what to say to her. The scary thing about cancer is that it is always uncertain, even after you cross into the safe zone. One can suddenly be pulled away from that zone again. It reminds me of something about the nature of the support group. For instance, members often talked to each other about the shared features of their experiences, and it certainly gave us a sense of connection and belonging. However, an episode such as Nishi-san's reminds us of the ultimate differences in how one's own cancer plays out. After all, we are all biologically different. I witnessed a number of occasions where one of the members disclosed his or her bad news to others, or somebody told me the reason one of them was not showing up. This time it was my turn. I feared what awaited me. Yet, strangely enough, compared to my first diagnosis, I did not feel I was totally alone, even though the situation was worse than the first time. This was probably because I had my Norwegian girlfriend, Hedvig, and her family with me and we decided to also tell my family in Japan. At the same time, I gained awareness from the people I met in the group that I was not the first person to go down this path, since many had already gone down this deadly road. I could think of Nishi-san and others ahead of me. To me they were my *sempai*, my Japanese mentors, who guided me and showed me how to face my destiny on the deadly road – guidance I highly respected. According to Lebra, *sempai* is a paring up and forming of a unit with a *kohai*, the junior member of one's *sempai*. It is a hierarchical relationship, and forms in various social relationships (2004, p. 48). Seeing myself as their *kohai*, I could see my own potential fate in relation to theirs. Indeed, Nishi-san used to talk about the importance of showing her own *ikizama* (one's attitude toward life) to those who come after her. I was at the crossroads of uncertainty where I too had to consider my own *ikizama* to those who may come after me.

My Norwegian oncologist told me in fluent English that it was more likely a relapse than a new cancer. But I understood that my condition was more serious than before because the oncologist did not say things like it is “easy to treat”. Hedvig, who was there with me during the consultation, later told me that I instantly lost all colour in my face. What I remember is that I immediately felt a numb sensation in my chest, my face, and at the back of my head, as if my old sense of self was melting under the



rise of a new awareness that my fear of reoccurrence had finally come true, and there was no return from this point on. But still, somehow, I felt as though I could return to a time before the diagnosis, because I could still recognise my sense of self and the atmosphere before the diagnosis quite well. I tried to hold on to that sense again and again to see if I was still the same person. More precisely, I was repeatedly trying to *reset* this reality and to *restart* the time before the diagnosis, just like the RPG computer games would let users restart the game from where they saved it (known as a save point). But my new awareness kept reminding me that the diagnosis had taken place. It was as though I had accidentally saved the game right before this terrible situation, so that no matter how many times I restarted it, I always ended up with “game over”. When seeing this episode today, I see that the diagnosis seemed to have an immediate and powerful effect on the transformation of my identity, and the point when I was given the diagnosis was another “punctuated time” (Guyer, 2007) in my personal history. In fact, when I try to remember things around that time, my remembrance is coloured and closely related to an episode where I had to endure extreme pain from a bone marrow biopsy. But where are the other memories? Since lived experience is never merely one thing after the other, but rather a multiple of intertwined dynamics, I must also have had other kinds of experiences, even things which felt positive, fun and interesting in the midst of a time of extreme uncertainty. However, I have difficulty remembering them.

Like my American oncologist, the Norwegian oncologist gave me some hope through the prognosis. He said that they still thought they could save my life and it was even possible I would be cured. I imagined how other patients would feel hopeful and reassured in an instant, and how he probably thought I would feel the same. However, it was equally shocking to me to hear what he had just said. “Possible to save my life? How come”? It is supposed to be “an easy cancer to treat”! Such thoughts went around in my mind, and I became more upset. He seemed to be a bit confused by my reaction, and reminded me once again that it was still curable. Still being upset, I told him things my American oncologist had told me. He did not comment much and instead said calmly, “It is never good news if cancer comes back”.

But how come? Why was I having a relapse in the first place? Did it mean my American oncologist had not given me proper treatment? I was confused as well as starting to feel angry towards the American oncologist, as if he had betrayed me. The Norwegian oncologist told me that he could not tell me more unless he received my medical record from the US. I just could not believe that I might die from a curable cancer, something that was “easy to treat”, the kind of cancer my American oncologist would choose to have himself if he had to pick one. It meant that if I died from it, I would end up as one of those extremely unfortunate cases, I believe within less than 10 percent or so according to the survival rate. But why now? I was not feeling particularly sick or weak around that time. I actually thought my health condition was good and the blood tests showed no signs of cancer. In fact, just a few months earlier, during my fieldwork, I was at the peak of Mount Fuji, the highest mountain in Japan at 3776 metres, while filming Marsha-san and the people from Ippo Ippo with my big camera (see Figure 4). It was a two-day project with eight hours of climbing the first day, and then a few more to reach the top on the following day. And I managed to do it all. I remember the group leader being worried about me before the event because he was not sure I could do it, since previous experience of professional TV crews who had followed them giving up halfway because they were so exhausted from filming while climbing for hours and hours.



*Figure 4: Wake with a big camera at Mt. Fuji, 2009. Photo by Ohashi-san.*

Even looking at this picture today, I simply do not recognise any trace of weakness or illness. Yet, strangely enough, the reoccurring cancer must already have been there inside my neck, without my having any awareness of it. Since it is a slow and less aggressive cancer, it had not caused any negative effects on my health yet. Indeed, I must say that I look quite healthy and energetic, enthusiastically participating in the group's yearly event as a researcher with a big video camera in my hand. I do not look at all worried about whether or not I could manage filming all the way to the top.

But the second diagnosis immediately broke down my sense of confidence about my health. Confidence in my health had become extremely fragile since my first diagnosis. It made me realise how important the American oncologist's phrase "easy to treat" was to me, and how much I had been clinging on to it. In fact, even when I discovered that, after coming back to Norway from my fieldwork in Japan, I could feel a small lump in the same area of my neck again, I tried to reassure myself by repeatedly thinking, "In the worst scenario, I could get rid of it once again if I could just bear the treatment". It would be tough, but I knew I could manage it since I had done it before.

However, this self-made hope easily cracked into pieces when my Norwegian oncologist informed me that they were considering the standard, hard chemotherapy on me this time. My treatment in the US was of a mild type so that I did not have to lose my hair. “The hard chemo!” It frightened me because I had heard how terrible it was for my *sempai(s)* in Ippo Ippo in Japan. They talked about how it ruined their sense of taste and smell, how it dramatically weakened their physical strength, and how they struggled with desperate fatigue and continuous nausea. “Look what it has done to my nails, chemo is poison!” one woman expressed while holding up her hands. Her nails were purple. Everybody else looked uncomfortable, and did not say much to contradict what they had just heard. This is one of the negative sides of hearing stories from cancer peers; it elicits a powerful imagination to anticipate the future as though I will experience something exactly like them. Marsha-san later personally told me that chemo also saved her life.

My Norwegian oncologist was rather like my American one, but very frank in his opinion. When I asked him about my hair, he recommended that I cut it very short so that I would feel less of a shock when I lost it. “It will soon grow back again”, he said with a smile. I also asked him, “What is it like to go through the chemo?” He reminded me that it varies upon how each person responds to the medicine, but I could think of it as “carrying 20 kilos in my backpack”. That sounded very hard, although something I could imagine. I saw he had some professional photos of beautiful landscapes of Norwegian mountains on the wall. He told me that he had taken them during his holidays when walking in the mountains. I kept looking at the photos. I recalled the feeling of being at the top of Mt. Fuji, looking down at the gorgeous landscape. I realised that the oncologist took the photos while carrying heavy gear. He was using a metaphor that he could recognise himself as a mountain climber. Suddenly the new idea hit me, and I told my oncologist, “all right, if you say I have to carry 20 kilos more, then I will train myself more so that I can handle that extra weight.” I somehow felt encouraged, though I still felt shaky. He told me that some physical exercise would be recommended, but that I should listen to my body during and after the chemotherapy sessions. I strongly hoped I could maintain my physical strength through training, because this was a strategy that worked in the US to maintain my

motivation and optimistic attitude, which I had learnt from Armstrong. However, I later discovered that that was just wishful thinking, because chemo did take away most of my physical strength, and it did not come back as quickly as I had hoped. Becoming physically weak was shocking. I remember I became agitated and miserable and would for instance react strongly, nauseous after a new round of chemo, when Hedvig tried to encourage me that it would soon be better. All I wanted to hear was for her to acknowledge the struggle I felt in the moment, to be with me in the pain: “It must be very hard to be so nauseous”. I know now that her intentions were good, but there was a mismatch of empathy. This was not what I needed at that moment, and in addition I was not able to see her intentions and be open to empathy. It was not easy to be me, and it was not easy for her to be around me. Despite the struggle to adapt to the situation of being weak, I was not angry with my Norwegian oncologist because he had honestly told me that it could be hard. I appreciated his realistic estimate of what I could expect during the chemotherapy and afterwards. He probably foresaw that my training project during chemo would not work as I imagined. Instead, he reminded me of the simple fact (which many people tend to forget) that I needed to be careful with my own body and its limitations during the chemo.

Since I had to go through yet another, and tougher, cancer journey in Norway, I wanted to choose a different attitude this time. I would not be a passive dependent patient in the traditional Japanese sense, nor would I be a hyper-positive cancer survivor. I believed that I was now more experienced and knowledgeable about cancer survivorship for several months before I had come back from my master’s fieldwork with Ippo Ippo in Japan. I met many *sempai* and I learned a lot about respectful attitudes with which to face this hard reality. They taught me the value of taking charge of one’s own cancer journey during oncology care, specifically the importance of *studying* one’s own cancer, the treatment and its side-effects by informing oneself about new and medically accurate information available through various sources (hospitals, the internet, and peers). Yes, I would like to go through this with a proper academic attitude by turning this awful situation into the field of my study, as though I was simply conducting fieldwork in the world of Norwegian oncology care. I could use myself as a research instrument to obtain ethnographic data for cross-cultural

comparison between the US and Norway. I felt like I was going in the right direction, just as an experienced cancer survivor, not simply being positive, but being constructive. I somehow believed if I saw and interpreted the world around me with academic curiosity, with a sense of wonder, then I might be able to handle the situation better, despite any potentially uncomfortable circumstances, such as the examination by the trainee in the US where I ended up feeling like an object.

## *2.2 The Norwegian Cancer Patient with Disney Comics*

I was probably the only Japanese person ever to have received cancer treatment in Tromsø, one of the northernmost towns in the world.



*Figure 5: The city of Tromsø. Photo by Shotaro Wake.*

I was open to my family about my second cancer diagnosis and treatment, and communicated with them through email and Skype. Hedvig was studying in Copenhagen at the time, so she and her parents visited me as often as they could, but I still had lots of time on my own.

My departure on the second cancer journey started with a memorable, but to me a puzzling, encounter. I had to be hospitalised one day for various check-ups. The university hospital was crowded at the entrance with smokers and people waiting for

a taxi and I did not feel comfortable at all about the department where I was going. It was somewhere at the back of the hospital, a few floors down from the entrance hall. I saw old patients in their rooms. They looked weak and sick and made me afraid that soon I would end up like them, when my strength after treatment had been ripped out. I was brought into a room where there was already another patient. He was an overweight middle-aged man with a short haircut. I saw some tattoos on his arms. He looked very tired and not well at all. As my Norwegian was as bad as his English, we both kept quiet. From time to time he coughed horribly, which made me think he might have lung cancer. The cough was so intense it was like a hoarse groan, and it continued for some time. I could not see him because of the curtain between us, but I could hear how he struggled to manage the cough and when it stopped, he tried to catch his breath. It was a surprise to me that he often went out to smoke a cigarette at the entrance. I could hear him trying to lift his body from the bed, looking for shoes to wear. I could only see him when he left the room with a wheeled IV stand. That was the time I felt I could breathe and relax a little. Whenever he came back with the strong smell of the cigarette, he again had to cough terribly, and for a long time. I nervously had to listen to another round. I wished I could change rooms, but I did not feel comfortable asking my nurse, who did not speak good English.

What I struggled to understand was why the man was still smoking in the middle of his cancer treatment. He seemed to contradict the whole purpose of receiving treatment, as smoking would no doubt have a negative influence on the effectiveness of the chemotherapy. Why did he not want to be better? Or could he no longer expect to be better? And if so, what was he doing here? I might have been irritated because he was a different kind of patient from my ideal type. He was no Lance Armstrong. In addition, I was different, and I had to be different to survive this situation the best I could. I too used to be a heavy smoker until the day I received my first cancer diagnosis. I quit smoking at once, and have never touched a cigarette since, nor have I had any desire to smoke since then. This came as a surprise to me because trying to quit smoking had never worked for me before. It showed how desperately I wanted to survive my cancer, and quitting smoking seemed like an expression of my will for a positive change to be better and healthier. Maybe I needed protection and assurance



when facing an extreme and chaotic situation, and quitting smoking was a nice and easy thing for me to attack as a symbol of cancer. When seen in this light, the Norwegian patient seemed to be one of those “bad patients” or “difficult patients” who simply did not follow the doctor’s orders.

Once, late in the evening, I passed next to my roommate’s bed on the way to the bathroom. He was lying on the bed reading something. I saw that he was quietly reading a Disney comic. I somehow felt sad. He was probably 50 something or more, and the only book he wanted to read was a Disney comic. When I think about it, the world of Disney is something completely opposite to the world of cancer. It has no disease, no suffering or death. It only fills you with comfort, hope, dreams, joy and love. It seemed he was seeking something comfortable and easy. Yet, he did not seem to enjoy reading at all. He looked at me without saying anything, then dropped his eyes to go on reading. That gesture made me realise how worried and frightened he was too.

But why could I not be more friendly to him? Where did it all go, the things I had learned from the group members in Japan? They taught me the value of companionship and friendship as cancer survivors. I should have applied what I learned from them, such as how seemingly small gestures, for instance making small talk with a sense of humour, could warm up the relationship between people and the atmosphere around them. I could simply have said “Are you ok?” to him after he coughed, and I am sure he would very well have understood that I was trying to comfort him. At least, he would know his roommate was not ignoring him or dismissing his suffering. Also, why could I not try to put myself in his place, be empathic, and read his underlying concern through his behaviour? For instance, smoking and reading comics may have given him a sense of control in this terrifying life situation, especially as he was staying at a hospital where patients often cannot easily find peace. Being able to connect with him in this way could have been a way of making the atmosphere of the hospital room a bit more friendly, comfortable and a safe place, for both of us. I should not have forgotten that I was reading something similar, a book of comfort like Armstrong’s book, to endure being in this

uncomfortable life situation. He was not reading comics to seek guidance, maybe he just wanted to laugh a little and for a short while to distract himself from his suffering, so that it might be easier to get some rest.

This episode highlights the recurrent themes of empathy throughout the thesis, especially the relationship between one's own illness, health concerns and traumatic experiences, and one's ability and capacity to give and receive empathy, in line with the issue of empathy presented by the discussion of Hollan and Throop (2008) (see also Chapter 1). Something so naturally ingrained in a person and so helpful when meeting others, empathy can still so easily disappear when facing personal hardship, at a time when a person is actually more in need of the flow of empathy. The important point in my short story from Tromsø is not whether my own interpretation about the man's motivation for smoking and reading is true or not. But if I had been able to imagine him in this way while we were staying in this room together, I could have been more creative in being friendly to him, and the atmosphere in the room would have lightened, and perhaps made it a safer place for both of us. But, maybe I was too scared to face cancer a second time.

## 2.3 Meeting a Sempai during my Second Cancer Journey in Norway

I was searching for a new approach to my second cancer journey when I came across a book called *Stranger in the Village of the Sick: A Memoir of Cancer, Sorcery, and Healing* (Stoller, 2004). The book had a powerful influence on me at the time of my treatment in Norway. My supervisor had recommended the book to me. She informed me that the author, Paul Stoller, was an anthropologist, and expert on the Songhay people in Niger and Mali, as well as West African immigrants in New York. In this book, he wrote about his own cancer experiences. I quickly ordered the book with the hope I might learn something drastically different to Armstrong's approach. I wanted to know how a trained anthropologist like Paul Stoller would go through his cancer journey. I wanted to know how the author was able to turn his own experience of cancer into an object of study to critically examine and explore in depth. This sounded quite brave to me, because personally I preferred not to think too much about my own experience. In fact, although I had just come back from fieldwork with Ippo Ippo in Japan, my interest was to learn from the experiences of others, not from myself. I wanted to know how *they* experienced their cancers and how *they* cultivated ways of dealing with difficult life conditions. I had little awareness that I was already repeating the same pattern in my behaviour. For instance, I was seeking an ideal model that I could imitate when I encountered obstacles in my life.

By reading the book, I discovered that Stoller had a similar type of lymphoma to me. I felt that this made our connection more unique and specific, especially since I learned cancer is no longer understood as one disease, but rather had become a polythetic term organised in over 200 different subcategories within biomedicine (see for instance Mukherjee 2011; Cancer Research UK, n.d.). I recall that I also felt the same special connection when I was introduced to Noji-san in Ippo Ippo. She was the only person who had the same type of cancer as I did. It was nice to know she was doing quite well after her treatment five years later. She was busy volunteering as an

assistant to hearing impaired persons. Therefore, in the same manner, I was very curious about Paul Stoller.

I learnt through reading the book that Paul Stoller had his cancer treatment 10 years previously, and his cancer condition is in remission. I very much admired how he made use of both his knowledge of Songhay sorcery as well as the knowledge of 30 years of training in anthropology to cultivate his respectful attitude when going through his cancer journey from the point of diagnosis and treatment to life afterwards. In particular, I was amazed at how he communicated with his oncologist. Stoller clearly seemed to be overwhelmed by the experience of rapid change, the violent start of receiving the bad news and then being given instructions for his first treatment plan. It must have something to do with the fact that this transitional process goes quickly in the eyes of the patients, although not in the eyes of the oncologist, for whom this is a daily routine. At one point, Stoller invites his oncologist to recite *genji-how*, an incantation of Songhay sorcery that he has learned from his teacher Adamu Jenitongo. Stoller sensed a sceptical look from his oncologist, who is asked to hold Stoller's hand. Stoller said to his oncologist:

“There are different paths to well-being,” I explained softly. “You have your way of treating illness. I learned another perspective from my African teacher. I would like to rely on both now.” I paused. “This treatment will bring physical and emotional disorder, pain, and suffering to my life. Disorder deepens illness. If I am going to get well I also need to follow the old ways of the sorcerers. I will try to harmonize the world in the way my teacher taught me. This will help me cope” (2004, p. 79).

Stoller is probably right that *genji-how* helped him cultivate his own strength to face the following cancer treatment. However, there is more, something remarkable in my eye, in that Stoller managed to harmonise the relationship with his oncologists. Since I had only been following my oncologists' instructions, I was amazed that Stoller took the initiative to invite and allow his oncologist take part in his small ritual during the consultation. He was taking charge himself. I could not imagine myself suggesting something like that, even if I knew something as remarkable as this. What I noticed is

that there seemed to be a shift in roles between them during the ritual. Stoller became the teacher and the one who knows, and his oncologist became the student and learner. But what are the consequences of a shift in role between patient and doctor? Usually it is the case that the teacher is the person who controls the pace and sense of space during the lecture, and in this case, *genji-how* allowed Stoller to create a ritual space where he could affect the pace of the consultation, which would otherwise be difficult for a patient to do.

Thus, by inviting his oncologist into the ritual space, Stoller managed to pause and slow down the pace of the oncologist, who was otherwise going too quickly. Roelsgaard Obling wrote in a recent paper (2013) that patients find it more and more difficult to have their emotional needs met by doctors because the cancer treatment programme in Denmark (and likely elsewhere) has been ever “accelerating”. She writes that the hospital is under constant pressure to institutionally reform and provide efficient cancer services, although it has certain negative consequences for both the doctors and patients:

The standardisation of work tasks in the accelerated pathways hinders that the doctors develop a total impression of the patient, and consequently it becomes difficult for them to assess the emotional state of patients and adjust their professional ethos to this (Roelsgaard Obling, 2013, p. 444).

She suggests that doctors could easily miss the emotional needs of patients (which is constantly changing) due to the fast pace of the consultation. I felt like the pace in my consultation was often influenced by my oncologists, and I have heard some women in the support groups complain that their doctor, in their eyes, acts like he is very busy. Such impressions made them hesitant to ask too many questions, though I imagine that every single question they might have would be an expression of their emotional needs.

What I see is that after the ritual the oncologist starts to pay better attention to Stoller as a person. The oncologist became curious about Stoller’s academic background. At

the same time, I should not forget the oncologist decided to join in with the ritual. He could always have withdrawn from the offer, but he let Stoller take his time in a way that his patient found comfortable. Many oncologists would agree that they aim to make their patients comfortable during the consultation, but I suspect they often prefer to do so in a way they themselves find comfortable. I found this episode a beautiful example of how the mutual respectful relationship between patient and doctor is nourished, even though time is quite limited in a clinical encounter.

Stoller's story still continues to grab my attention to this day. After the diagnosis, the oncologist suggested that Stoller studied his disease and treatment options. The oncologist gave him some trustworthy websites that held "a great deal of information on lymphoma" (2004, p. 60). From my point of view, this kind of approach would do nothing but provoke anxiety, but Stoller interprets the oncologist's suggestion as a means of reducing his anxiety. I became curious about how he dealt with the diagnosis and the oncologist's suggestion. There is no doubt that the bad news hit him hard. Although he was trying to maintain his daily work routines and leisure activities, he wrote, "nothing could keep me from thinking about what was happening to me. I worried constantly about my future" (2004, p. 71).

However, despite his worries, and something which came as a surprise to me, he writes that he spent hours reading not only the recommended websites, but also medical literature about his disease and chemotherapy. Medical literature critically differs from "light reading", such as websites or books designed for people afflicted by cancer. This light reading tends to be concerned with the comfort of their readers, with the intent of avoiding the elicitation of unnecessary emotional burdens and shock on the readers. However, medical literature on cancer, or on any other illness for that matter, is designed for health professionals and academics who directly deal with hard facts. Their readers are interested in knowing how to cure diseases, but also how the diseases weaken and sometimes kill the patients. Such literature omits any comforting presentations that would buffer the burden of knowledge for those who identify themselves as subjects of the paper in question. In this sense, by choosing to read such literature, Stoller steps into the subject field of the oncologist.

I admired Stoller's courage, although I also got an impression that his reading made him somewhat concerned. I became curious about what he had discovered, and saw that there was a footnote in the text. I found it difficult to fully understand what it said because of the unfamiliar technical and medical terms, but still I picked up some phrases that I could understand, "[...] for the most part, an incurable disease [...] almost all patients will experience disease progression and ultimately die of their disease [...]" (2004, p. 208). I was shocked and closed the book at once. "What does it mean that all patients die at the end? Is that also true in my case?" It certainly seemed like that, because, after all, we had a similar type of cancer.

I felt bad due to what I had just read in Stoller's footnote. It was evening and I was alone in my room, left with an anxious feeling. I wished I could find out if my understanding was correct, although I did not feel like reading the section again. I wished I could ask my oncologist about it, although I knew there was a week before I was scheduled to see him again. But how would I know if he would admit this was also my situation? If my understanding was correct, then my doctor's prognosis was his way of instilling hope in me, while at the same time he probably suspected I would not respond well to my treatment. One anxious thought that came with a "what if" triggered another, and I kept ruminating on them. I wished I could stop them, but back then I did not know how. Today I see that I was struggling with the seemingly impossible task of trying *to stop* my thoughts, instead of *coming to terms with* them by becoming aware of them, and then letting them be as they are without giving away any (mental) energy. This is the core teaching of *mindfulness* by Jon Kabat-Zinn (2013), which I have since become a dedicated practitioner of, but not until six years after this episode. The practice is now helping me a lot.

I carried Stoller's book with me on the day I started my regular sessions of chemotherapy. My nurse asked me to sit and make myself comfortably in an armchair while she prepared for my treatment. The infusion room was nothing like the one I stayed in overnight when having the biopsy. On the contrary, it was filled with warm and peaceful sunlight through the windows, and I could see the gorgeous fjord and a

mountain range. The nurse was in a good mood, preparing my IV stand while she hummed cheerfully. I opened Stoller's book to read once again the section that would prepare me for this occasion, the section where Stoller described his first treatment. I did not know how to recite *genji-how*, but I knew Stoller through the book. The nurse asked me what I was reading. I told her about my study and my unique connection with Stoller through cancer. As she showed interest, I told her about my recent fieldwork where I joined a cancer support group in Japan. I felt somewhat proud of myself since I was not too nervous in making small talk with the nurse. I saw she attached a red plastic bag on my IV. I said to her, "Oh, that red bag! Do you know they use the same in Japan?" I remember some women who had chemo complaining that it took a while for them to stop associating red with nausea. They did not want see anything red while eating or drinking. She told me this was understandable, but that I did not have to worry since medication for nausea had improved a lot today. She also told me the following episode: there was a time when some patients felt like throwing up when they saw her on the street. That made me laugh a little, especially because such an awkward encounter would have seemed impossible to prevent in downtown Tromsø, where 10 minutes is all it takes to walk across the city.

I became more nervous as I saw the nurse getting ready. I was suddenly hit by the awareness that I was not ready, although I had been acting like I was. I felt a strong urge to escape. I could not help but ask her why I could not have the same medicine Stoller had, since we had a similar type of cancer. That would give me fewer side effects. She stopped her hands for a moment, and reminded me gently that doctors today no longer give a standardised chemotherapy treatment for all cancer patients. Even though I had a similar type of cancer, the medicine could still vary. She told me softly, "Your cancer is curable, but his is not."

I could not help saying, "But if that is so, why I am here today?". I tried not to show her my tears. She gently said that it might be a good idea for me to leave the book aside and concentrate on my own treatment. To be honest, I felt relieved by her advice. I must have felt overwhelmed from the impossible task of keeping up with the ideals. So, I closed the book and my eyes and let the nurse do her job. And I concentrated on



my recovery. It was the moment when my cancer journey drifted apart from Stoller's. I felt a sense of assurance with my new awareness. Instead of pretending to be like someone else, pretending I did not have any negative feelings, it was OK for me to be myself, and it was OK to feel what I was feeling.

When thinking about this episode today, and as I see myself struggle from the burden of knowing and knowledge, I wonder what made Stoller read information beyond something recommended by his oncologist. Was that his way of gaining control, although, to some degree he seemed to be negatively affected by the burden of knowledge? As I started to read the works of scholars who themselves have experienced cancer, I noticed the same behaviour of willingly seeking knowledge from beyond the comfort zone of many patients, including myself. For instance, Jackie Stacey, the author of *Teratologies* (1997), reflects that "my own response to being diagnosed with cancer was to read as much as I could about the subject." And she continues:

The desire for knowledge was clearly a bid for control at the very moment it had been taken away from me. It was also an instrumental use of the academic skills of my world and a way of making the alienating medical world, in which I had suddenly found myself, more familiar and more manageable. Unlike many other people with cancer, who do not have my educational advantages, I did have a powerful set of resources to draw upon. Turning the disease into a research project channelled my otherwise overwhelming fear and panic. The desire for information, and the confidence to access it, is often the privilege of those with certain educational histories and race and class backgrounds, but also belongs to a new generation of what I call 'participatory patients'. On the whole, my parents' generation, for example, have far less inclination to be put in the picture. They are happier to leave it to the medical experts and to avoid the burdens and responsibilities such knowledge might demand. But those of us who have been influenced by the information cultures of the last twenty years are more susceptible to the desire to know and to the fantasies of knowledge as power (pp. 3-4).

By reading Stacey's work, I see there is a tension between the two ways of facing the uncertainties a serious illness like cancer brings. In one group, there are those who

have high academic skills, at the level of doctors, who are well equipped to handle information in the face of ongoing uncertainty, in order to re-establish their sense of control. The other group is not trained to the same academic level, and more often rely on medical experts whom they have to trust holds the right information for them. A common expression for this latter strategy could be: “The doctor knows best”. On the one hand, this may appear to give the individual less control over their situation, since to be informed provides control. However, having to carry “the burdens and responsibilities such knowledge might demand” (Stacey, 1997, p. 5) could also be seen as a significant drawback. In some cases, it may feel more comforting to rely on the doctor, as Stacey’s parents had to.

What Stacey helps me see about myself, in relation to Stoller and to those I met in the support group, is my lack of self-confidence in academia. While I truly admired both ways of dealing with uncertainty I was not fully committed to either approach. I was not devotedly seeking knowledge through various sources, nor did I sincerely trust my Norwegian oncologist, mainly because I felt insecure because of previous experience in the US. It made me realise a simple fact. To imitate someone cultivates an observer’s skills only to a certain extent. Complex skills come through long-term commitment and dedicated practice.

Therefore, employing academic skills to cultivate a sense of control when facing uncertainty seemed to be one way of dealing with uncertainty, and it certainly helped me in the process of coming to terms with my story. But what about those without an academic background? In what ways are they able to reach out? When I went through my cancer treatment overseas in Norway I came to experience the forms this empathic encouragement could take from members of Ippo Ippo, based on the trust we had already built in our relationships.

## 2.4 Video Messages from the Group Ippo Ippo

After my second cancer treatment, the group members of Ippo Ippo sent me a number of emails to support and encourage me. In particular, there are two video messages from the group I would like to share that show their positive and empathic support towards me. The following video messages (Figure 6) were sent to me the day before the students' film screening, organised by the department of Visual Cultural Studies at the University of Tromsø. During this event I was going to show my master's thesis film *Ippo Ippo*<sup>3</sup> (Wake, 2010. 47 min). The film follows Marsha-san, a middle-aged wife with a history of breast cancer, poor eyesight and osteoporosis, and her first challenge to participate in the group's annual event of climbing Mt. Fuji. For the screening, I asked the organiser if the group would like to send a short video message to the Norwegian audience who were just about to watch the film. I thought it could work as a nice gift to the audience, and I hoped they would enjoy receiving something specially made for them, for this occasion. I was thinking that the group's message might help to personalise the audience's viewing experience, so that it would further strengthen the audiences' emotional relationship to Marsha-san and the people in Ippo Ippo. I hoped that this occasion would boost cross-cultural communication between two groups if only on a tiny scale. I was very much into the idea of empowerment, sharing, and dissemination. The first video (see Figure 6 to the left below) was recorded by Marsha-san using her mobile phone at her home one day before the screening, as a trial to see if recording and emailing would work at all. The second video was recorded by a member of Ippo Ippo during one of their meetings in front of the group flag (see Figure 6 to the right below).

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<sup>3</sup> For readers who are interested in viewing the film, click here to watch it:  
[Ippo Ippo \(2010\)](#)



Figure 6: Screenshot of video message from Marsha-san, 2010.

Clink here to watch the video: [Video messages from Ippo Ippo](#)

I thought the group video contained a friendly message the Norwegian audience would appreciate during the screening. In the video, the group is smiling and laughing energetically in the way they address the audience. Their positive attitude, friendliness and openness are of a particular aesthetic in Japan, which was also expressed through the way in which they collectively sat together, folding their arms around their knees and straightening their backs. As Marsha-san said in the video<sup>4</sup>, they are interested in sending their “energy” to the Norwegian audience, and I thought the message was visually well expressed, even if the audience might not have been familiar with Japanese customs. But a gift may not look proper or as though it is given with respect without being nicely wrapped. According to Joy Hendry, who wrote a book entirely on the notion of wrapping in Japan:

A Western perception of the practice prepares us to regard wrapping to obscure the object inside, whereas in a Japanese view it would seem that the function of wrapping is rather to refine the object, to add to it layers of meaning which it could not carry in its unwrapped form (1995, p. 27).

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<sup>4</sup> All translations from Japanese by Shotaro Wake, except the transcriptions of the film *Ippo Ippo* (2010) and *To the Last Drop* (2016) which were by Gary Kildea and Shotaro Wake.

Having grown up with Japanese customs, I wanted to wrap the videos in a way that would present them respectfully to the Norwegian audience. My years of living in western countries (the US, Norway and UK) have taught me that people often appreciate a surprise gift. According to Hendry (ibid), Westerners value the element of surprise through total concealment in the way the wrapping is done, while this is not automatically the purpose of a Japanese wrapping. Therefore, to surprise the audience I made a special arrangement with the theatre technician and asked him if he could play the video at the very end of my Q&A session after the film had been screened. I kept my mission secret because I wanted to present my audience with a nice surprise.

A five-year span helps me to see what really matters, even today. What once appeared to matter seems less interesting today, and things I did not give much attention to may have become more important. When I was screening the event, I thought the audience's response would matter, not only for me, but also for Ippo Ippo. And in fact, they were delighted when I told them of the various responses from the Norwegian audience. However, five years later, there is no trace of any cross-cultural communication that I dreamed about then. I never heard the group mention it again, and I certainly did not have the possibility of getting a later response from the audience, whom I did not know. In fact, I might be the only person who still remembers and talks about this day. Now what seemed so important to me then becomes less so.

Instead I started to notice different things in the video from Marsha-san. I thought the main reason for the video was to use it as a test for screening the following day. But, when I paid more attention to her message, I started to notice a deeper meaning. She seemed to be using this occasion to indirectly encourage me in a considerate and sensitive way. On the surface, and if unfamiliar with the traditional Japanese communication style, it may seem as though she is only talking about her own challenges in the video, rather than her message being an expression of support to me during my cancer treatment. However, it seems to me she wanted to show me that her

challenge was the same as mine, guiding me to take on a positive attitude, *maemuki* in Japanese. *Maemuki* literally means “facing forward”, and this behaviour is to be understood as looking to the future with a positive mind-set. That gave me a powerful feeling of connection and sharing. Indeed, Mt. Fuji was our collaborative project where I followed her as a visual ethnographer. I knew exactly the effort she had to put in when climbing the mountain with her health challenges, just as she knows exactly what it is like for one to go through cancer treatment. In both a personal and empathic way, she was telling me she was thinking of me. This is a good example of Japanese people’s preference for an indirect communication style, or “high-context” communication style (Edward T. Hall. 1989; Joy Hendry (1995; 2001)), where they rely on hinting or using subtle nuances. Though speaking indirectly could be confusing (see my interaction with Ishida-san in Chapter 5.3), it also offers interesting possibilities for Marsha-san and I. A space is opened up for empathy to take place, as the things Marsha-san does not say become a space for hope where my interpretation and her message meet.

Once I became more aware of how Marsha-san was trying to show her care towards me through the video, I also started to see the group video in a different way. Although indirectly, I started to see that they too were trying to encourage me and remind me of our connection. For instance, although the group organiser Ohashi-san addresses the Norwegian audience first and then prepares them for the group message, they are also addressing me by saying my name, some of them through their personal messages to me. I had been thinking that although the videos were made for the Norwegian audience, it seems now that they were made for me. Looking back, it seems strange I did not see the deeper meaning straight away as they addressed me in their familiar Japanese manner. It made me realise I had a double role during the screening. For instance, I saw myself only as a deliveryman trying to introduce Ippo Ippo to an audience in Norway. I did not see myself as the receiver of the video message. I initially thought the reason they said my name was because I was their reference and middleman to the audience, or that they may have felt too shy to directly address them. However, they were using this occasion to send a personal message to encourage me.

If the two videos were in fact self-composed gifts for me, I would like to respond to them respectfully. Joy Hendry writes about how to understand and receive Japanese gifts:

The problem may lie in our Western propensity to want always to be unwrapping, deconstructing, seeing the objects as the centre of things... what we need to do, is to learn to value the wrapping, as well as the wrapped, and seek the meaning they together convey (1995, p. 109).

So then, what is the wrapping and what is the wrapped in the two videos? To me, the wrapping seems to be their collective performance of sending the video message. They all behave *maemuki*, which is demonstrated by the way they talk, smile and laugh, enhanced by their organised way of sitting as a group, and lastly the way they wave their hands on signal. They exhibit the image of *maemuki*. It looks aesthetic to me, like the way a Japanese gift often comes with beautiful wrapping paper. If the performance is wrapping, then the wrapped, the content, might be the effort they put in by doing so. We then end up with three levels. At the first level, their effort relates to them trying to meet the favour I asked by sending the video. Their effort is also demonstrated at the second level by how they are being friendly towards the Norwegian audience. Finally, at the third level, their effort showed *maemuki* to me in a collectivistic sense, and it is at this third level, then, where meaning lies. Their *maemuki* has a special meaning because they know that I know they, like me, have ongoing health concerns and worries related to cancer. Through their performance and their effort, they try to encourage their peer, me, who is going through cancer treatment once again in a foreign country away from them, away from his family and friends. They are showing me that they too are facing similar difficulties, including existential worries. At the same time, they try to tell me that we have the choice of being able to deal with these ongoing difficulties in one way or another. They try to show their support by reminding me of our emotional connection and friendship. I now fully understand that these videos are expressions of their emotional support for me. It is like seeing a swan swimming on the lake, yet simultaneously, recognising that he is busy paddling under the water.

This understanding of people's effort as the centre of analytical entity has been quite a challenge for researchers. Alan Radley (2009) introduces a case of two men who had a bypass operation. In the following months, one of the men started to chop firewood in the backyard while the other started gardening again, although both knew very well that their wives and especially their doctors would disapprove of such actions:

This dramatization of everyday activity was a performance that showed they were well again, adding to any verbal claims that they might make about their recovered state of health (p. 11).

Interestingly, and what Radley points out, their performances are witnessed by their wives as well as by the researcher, and the fact that others recognise their efforts helps them to establish and restore their sense of health once gain. The actions of the two men seem to have therapeutic effects for them. Radley (ibid) states that:

When people fall ill they resort to whatever they have in their lives – their skills, resources, their relationships – to make sense of the future they have or, in some cases, have left (p. 14).

The performances of the two men described by Radley as an expression of their effort to make sense of a chaotic time, may be compared to the act of wrapping as the group of Ippo Ippo did in their videos. Researchers can try to understand how performance and effort, wrapped and wrapping, may help the ill person and his loved ones make sense of a traumatic past, as well as extend their sense of a future for the ill person. However, there is a methodological challenge for the researcher when trying to describe and explain such performances and efforts as the centre of the analysis. As Radley (ibid) states in the case of the two men:

Their actions were too fleeting, having insufficient form that I could hold on to. I needed something longer-lasting, something one might say that 'stands up on its own'. Addressing artefacts like published



stories and pictures allows sufficient time and space to describe the role of protagonists and witnesses, and to discuss the role of researchers in how such representations operate (p. 13).

However, I am more interested in exploring these intangible, fleeting actions as the centre of analysis. Especially as I discovered that this might be possible when I conducted a visual microanalysis of my own video-taped material, filmed in an interactive, participatory-observational film style, and importantly, when combined with follow-up interviews and further investigations.

As soon as I saw both Marsha-san's video and the group video from the perspective of their emotional support for me, it seemed obvious and straightforward. And then I had to ask myself what my condition was back then that made it difficult for me to interpret their message as it was: a normal Japanese way of approaching one another. Why did I persistently see myself as a deliveryman? I need to be more reflexive about my understanding of my cancer treatment, which was taking place around the time of the screening. Yet it is difficult to remember things that I actually do not remember well. Here, going back seven years works against me. I went through the photographs of the screening day. When I checked the date on the photos, I realised that I had a chemotherapy session the following day. It means that this screening was a break between two treatment sessions. Looking at myself I started to remember how I was quite affected by side-effects like nausea, fatigue, and physical pain – I tried to move carefully to avoid throwing up, my body and excrement smelled like chemicals, and I felt as though I was carrying a heavy stone on my shoulders, together with a pain when I moved as though a hedgehog had pricked me all over my body. When I think of my condition back then, it must have been physically tiring to give a presentation in front of a Norwegian audience, my head almost hairless, something I had not realised as it happened so gradually, but which I can now see in Figure 7 below, I remember I was nervous about how to present myself, especially deciding how much I should tell them about my current health. I did not want them to see me as a sick and weak person, or as someone dying from cancer. It required a lot of performance on my part to face the people I saw as healthy others. This performance itself may have

prevented me from deeply appreciating the intentions of both Marsha-san and the group, and what they tried to do through the video messages.



*Figure 7: My presentation of the film Ippo Ippo, 2010. Photo by Koike-san.*

Looking back, I can tell that receiving such a heart-felt gift from Marsha-san and the group during this difficult time was no doubt very important for me. I found an interesting photo that visually shows how I seem to be “under the spell” of the group’s collective performance (see Figure 8). The photos were taken by my colleague, and he captured how I was watching the group video from beside the screen.



*Figure 8: Ippo Ippo's video message played during a film screening in Tromsø, 2010. Photo by Koike-san.*



*Figure 9: Close-up of Wake when showing Ippo Ippo's video message, 2010. Photo by Koike-san.*

When I see myself in the close-up in Figure 9, I am amazed that I look quite peaceful, relaxed, and at ease – it does not look as though I am suffering from all the side-effects

I just described. Or at least, I did not appear to be concerned about my appearance as a cancer patient in front of the Norwegian audience. The group video in one way made me visible to the audience as more than just a film director, but a filmmaker who was undergoing cancer treatment. When I think about it, this sort of public recognition as a cancer patient was something I tried hard to avoid, but Ippo Ippo made it easier for me to come out as a cancer patient. I felt all right, even proud, to be looked upon as one of the group members. However, I still had a long way to go in accepting my cancer background.

## 2.5 *The two Stories meet again*

A few years passed, and shortly before departing for my PhD fieldwork in Kyoto, Japan, I had a memorable encounter with Paul Stoller. I attended as a speaker at the international conference “Experience, Sense and the Lens. Ethnographic Filmmaking, Visual Documents and Transcultural Knowledge”, organised by my former department, Visual Cultural Studies, at the University of Tromsø, Norway (NNDV 2012 Symposium in collaboration with NAFA). Stoller was invited as a special guest lecturer, and many, including myself, were looking forward to attending his lecture and to meeting this internationally famous anthropologist in person.

However, my motivation in meeting him was different to that of most others. I wanted to meet him as my *sempai*, whose path no one would voluntarily accompany him on; the life path of those who have experienced a serious illness like cancer. Although I still had a slightly guilty feeling for turning away from his book during treatment, I was nevertheless very eager to find out what kind of person he was, especially how he was doing ten years after the publication of the book.

I found him in a crowd of people eager to greet him. He looked very well and fit, with a clean haircut and trimmed beard, and presented himself with a sophisticated look. I carefully observed all his movements, his posture, his facial expressions, and the tone of his voice, to see if I could read and sense any trace of cancer experience in him, but I found none. This may sound normal for most people, but some of the people I met in the support group looked tired, worried, sick and weak, since they suffer from ongoing treatment or long-lasting side-effects. I remember he expressed his strong sense of wellbeing, vitality, and health during his guest lecture.



*Figure 10: Paul Stoller giving his guest lecture, 2012. Photo by Waage.*

For instance, he started the lecture by saying good morning to the audience sitting in the big conference room. Though he chose not to use a microphone, the strength of his voice certainly reached to the far end of the room. But when he noticed that the audience only barely greeted him back (and this might have been because it was the first lecture in the morning), he paused a little before he repeated “good morning”, but louder this time. This worked well, and the audience quickly responded with a bright tone in their voices as if someone had splashed water on their faces. From that point on, his lecture flowed. I tried to imitate him by not using the microphone during my

presentation. But speaking loudly to an audience was not as easy as it might seem. In the end, I thought I had done well. I found it satisfactory that in a way we had challenged the idea of health and sickness. Two former cancer patients talked without using microphones, while healthy others relied on technology to conserve their energy. When I asked someone in the audience about my performance, he said he could hear me well when I spoke towards the audience, but whenever I looked back at my slides, which I did occasionally, he had difficulty understanding me. This made me realise why Stoller held a piece of paper in his hand while giving his lecture, so that he could face the audience throughout his presentation. Similar to what I learnt from the experience of imitating Armstrong, the act of imitating someone else's performance could only work up to a certain point. Stoller's performance is "his", and something he had trained for through decades of teaching. In other words, his performance had a closely intertwined connection between form (delivery) and content (logic, reason), while mine did not.

I had a chance to talk to Stoller at the welcome party. "Oh, you must be Shotaro!" He welcomed me and asked me how I was with a genuine smile. As he knew a little bit about my cancer history through exchanging emails, I knew his greeting meant more than just being a phrase. I replied with a smile, "Thank you. I am good" and we shook hands. He later invited me to sit with him in front of a fireplace (see Figure 11 below). We both had a bowl of hot soup in our hands in a room where pleasant sunlight shone through the windows.



*Figure 11: Wake having lunch with Paul Stoller at the welcoming party, 2012. Photo by Waage.*

I was very curious about what brought joy and enthusiasm into his life. He was friendly, and made me feel comfortable to be around and ask him questions. He told me that he does daily physical activities such as yoga, walking, and cycling. I could not sense if side effects had left a scar on him. I, on the other hand, have been troubled with a tightness and an unpleasant sensation around my neck where I have had surgery twice, and it goes further down to my shoulder. He also told me about his pure joy and satisfaction in writing, especially as the very first thing he does in the morning before going for a walk in the forest near his house. I was amazed by the idea that he could write anywhere if he found a little time and space, even in an airplane, as he had no difficulty concentrating. I, on the other hand, did not even want to think about writing anymore since I had just finished my PhD research proposal for my fieldwork. I enjoyed almost nothing, as it involved reading and writing about issues related to cancer, illness, and dying. Why was I about to embark on more fieldwork in the world of cancer in Japan? I could have chosen a different research topic this time, things unrelated to my own traumatic experience. The only reason for me to remain in this



field was because I liked the people I had met in the world of cancer in Japan. It made me happy to think that I could see Marsha-san and the people in Ippo Ippo again. I could not wait to tell them about my awful experiences of second-time cancer treatment, while we would be joking and laughing together about various topics related to life with cancer and reminding ourselves not to forget that life should be more than cancer.

At one point, I asked Stoller if he still thinks about his cancer sometimes. He gave it some thought and said softly, "I think of it every day. It's always here." He raised his hand right in front of his own face. It looked like a mask that covered his face. Through the fingers, I saw his eyes and he caught mine.

### 3. Chapter Three

#### 3.1 The “Cancer Mask” and Continuous Liminality

Stoller’s reply with the gesture of a cancer mask made me realise that his experience with cancer was not yet over, even though 10 years had passed since he was diagnosed. He is probably still in remission. To be honest I was surprised by his reply because he did not seem worried, with his healthy looks, and the way he acted confidently and in a friendly way towards others. As a person who has experienced a cancer relapse, 10 years is a safe zone I wish I could get into. Some people relapse after only a few months, while I had mine after five years. However, he disclosed to me in person that his concern about a possible cancer relapse remained in his consciousness during those years. In fact, already in his book *Stranger in the Village of the Sick* (2004) he describes something similar to what I heard in Tromsø that day (“I think of it every day”). For instance, he writes about the experience of being in remission when he regained some strength after the treatment:

Remission, though, is a trickier enterprise than is treatment... Even though you feel “normal,” *you still think about cancer everyday* – if only for a little while... you understand that cancer is a traveller who may appear on your doorstep at any moment. How do you confront a life that cancer has complicated and perhaps shortened? Once in remission, some cancer patients become bitter and resentful. Others try to conquer their adversary (p. 190, my emphasis).

In this sense, he has always been waiting for bad news, as if a traveller would show up at the doorstep and whisper in his ear, “it is time to come with me now. No need to tidy up your room as there is no point of return in our journey.” From the way he honestly wrote about his concerns related to cancer, I felt relieved that I was not the only one with such thoughts. Still, to me it underlined the idea that I could go on

worrying even after ten years. In other words, Stoller confirmed he had not found a way out from what he calls “continuous liminality” in all those years.

Indeed, “Continuous liminality” is the hallmark of Paul Stoller’s book (ibid) as well as in his further works related to cancer (2009a; 2009b; 2012; 2013). The term is an extension of the concept of “liminality”, first introduced by Victor Turner (1969). Stoller argues that liminality is a typical phenomenon experienced by anyone who goes through a ritualistic process. In this process, liminality is often described as a transitional phase “between” the beginning and ending of it. During the transformational process, one’s social status is suspended until the end of the ritual where one’s status changes. Thus after the transitional phase, children are for instance considered adults, or a couple is announced as married. The feeling of uncertainty about the situation is released in the end. Stoller (2009) uses the notion of “the village of the sick” and “the village of the healthy” to describe one’s illness experience. For instance, when people become sick, they have to leave the village of the healthy, move to the village of the sick and stay there until they have recovered and their status can revert. However, for many cancer patients in remission:

The twist, then, is that the liminality of the cancer patients may subside, but it rarely ends. Even though remission brings on a relatively healthy state, there is, for all intents and purposes, no full-fledged return to the village of the healthy. This path marks a course of continuous liminality (pp. 147-148).

In short, one’s own being in the transitional state gets continuously extended. What about a case like mine, when I was diagnosed for the second time? I thought I was “out” of it when I made it to the five-year mark, which usually is considered as the safe zone, but still I received the second diagnosis. Did I go into another round of the continuous liminality, or did I misunderstand? Maybe I had never been “out” in the first place, and the second diagnosis just extended the path deeper into the downward spiral. Either way, I never found myself comfortable facing a never-ending uncertainty. It is well known that uncertainty can evoke various emotional reactions including worry, fear, sadness, and anger, and much research has shown that many

people experiencing cancer suffer from depression and anxiety (see, for instance, Akizuki et al., 2003).

But what is it that makes it particularly difficult, undoubtedly for many cancer patients, to be in this continuous liminality? Looking at my own source of worry and fear, continuous liminality is embedded in the fact that confidence and trust in my own body has been broken. My body has become a potentially dangerous arena for self-observation. I recognised the same in Stoller's writing, when he talks about his fear related to cancer:

If I have a twinge in my abdomen, I fear that lymphoma cells are again on the rampage. If an ingrown hair causes a bump to develop in my armpit, I think it may be a swollen lymph node – another sign of lymphoma. If the flu makes me sweat at night, I worry that this too is a sign that cancer has returned. When I get a CAT scan every six months I wonder if my time is up (2004, p. 193).

I respect his courage in disclosing something so personal to his readers, especially, as I have discussed in Chapter 1, considering his American cultural background where there is a strong pressure on individuals to be “strong”, and to conceal any sign that could be considered an expression of weakness. I could not recognise this sort of deeper insight into one's own fear in Armstrong's book (2001). Here, in the above passage, Stoller seems to look for signs of recurrence for his type of cancer, lymphoma. His oncologist had told him that “the onset of symptoms [would be] weight loss, low-grade fevers, and night sweats” (2004, p. 77). I assume these three factors were common symptoms for lymphoma patients in general, at least because my oncologist always asked me the same questions during my regular check-ups. For instance, “Have you lost weight?” I knew beforehand that he would ask me, but still I got anxious as it instantly elicited a thought such as “what if I have lost weight?” I did not know the answer because at one point I stopped weighing myself. I could easily have gotten obsessed with it, so I decided to follow my counsellor's advice that I should stop doing it.

Why I found it so difficult to deal with the idea of the three symptoms is that they are common experiences for most people. But, as Stoller wrote, a tiny and mild bodily sensation like the ordinary flu could easily turn into an alarming signal for a potentially life-threatening danger. Such interpretations elicit negative emotional reactions, which in medicine, researchers call “fear of cancer recurrence”. According to the most recent discussions on this subject in medicine, it is “among the most commonly reported problems, and one of the most prevalent areas of unmet needs for cancer survivors and their carers” (Simard et al., 2013, p. 300). I would like to stress the fact that fear of cancer recurrence is not just a personal issue, but also a collective experience, although I wonder how often the two groups have open conversations about their worries. In the case of Okamoto-san in *To the Last Drop*, he seemed to keep quiet about his concern. I am sure my family may occasionally think there is the possibility of relapse, although in the past 10 years or so I have never once heard them say they are concerned about this. But indeed, according to my wife, my parents have privately told her about their concerns related to my health and a cancer relapse. The patient and family aspect will be discussed further in the next section.

I would like to look further at the role of fear of cancer relapse in terms of continuous liminality. When I take a closer look at one of Stoller’s (2004, p. 193) phrases above (“If the flu makes me sweat at night, I worry that this too is a sign that cancer has returned”), I realise that there is an “in-between” phase of being uncertain, from the moment of discovering the sign until he concludes the cause of the sign is normal. The other two phrases (“If I have a twinge in my abdomen ...”, and “If an ingrown hair...”) also have the same structure in form of the anxiety provoking a “what if?” sentence. It made me think these embodied experiences are expressions of what Crapanzano means when he talks about “short-lived liminality”:

Short-lived liminality is often embedded in a protracted liminality in which the final transition is, as it were, rehearsed in a series of mini-transitions: the trials, tests, and ordeals in puberty ceremonies, for example. They are characterized by multiple repetitions in various registers. These include the evocation of mythic and historical events (2004, p. 63).

The liminalities he talks about seem to come to a resolution, and the person is able to move on. In *Imaginative Horizons* (2004), Crapanzano (2004, p. 63-64) takes a critical stance towards Turner's rather "flattened" view of liminality, where the transition processes move rather smoothly and in a linear way between the phases. Instead, Crapanzano highlights the dramatic quality of the "between" space, where the crossing of each mini short-lived liminality is a series of dangerous events in themselves, enhancing the tension toward its climax while evoking "anxiety and dread" during the course of that process. Normally, persons will come to the end of their liminality, and bring with them whatever wisdom and change was learned during the phase, which is meant to be a source of great relief at the end of the passage. However, for those afflicted by cancer who live in continuous liminality, the feelings of anxiety and dread often stay, and one could not expect a great relief after a long-lived passage of continuous liminality as one has encountered a never-ending series of mini liminalities. These mini-liminalities leave one with the intense feelings of ups and downs, like a rollercoaster that never comes to an end. These mini-liminalities leave one with intense feelings of ups and downs, like a twisting rollercoaster that never comes to an end.

I started to think that the very micro unit of a dramatic feature in each mini-liminality is perhaps one's negative interpretation of a bodily sensation, which fuels the thoughts of danger until it becomes more and more realistic to that person. Usually people do not worry much about having the flu, but I can interpret it as "I know this is nothing, but what if it is the beginning of something serious that relates to my cancer?" Such thoughts serve to open up an imaginative horizon where I could go on and on, spending time creating negative scenarios that may come true in the near future. What a waste of energy it was to have these types of thoughts that I kept ruminating on at the back of my mind all the time, without always being aware of it. The fear of cancer recurrence may be a unique feature for those who study it, but a nightmare for those who experience it.

In fact, to some degree it took a while for me to become aware of my thinking patterns and then dare to face them. When I finally discovered it, my wife told me she had repeatedly reminded me about it for some years. According to her, “they are such normal symptoms that anyone can have them, and most often it is not about cancer. Also, with your body type (being skinny), when you look tired, it somehow shows in your face. It is the same with my brother. It means that you simply look tired, nothing more.” But it felt as though I had never heard this before since I was probably fully occupied with my own anxious thoughts. Although she could see that I was repeating the same behavioural pattern, for me, I always felt I was dealing with a new idea based on a new physical condition in a new situation. I continued with the same minimalities, but in different shapes and at different times, with an increasing degree of anxiety-provoking strength, and each time they seemed truer. And these ideas were not only fuelled by myself.

Let us go back to the question about weight, “Have you lost weight?”. A seemingly innocent comment that immediately makes me feel trapped in permanency, demonstrating how a simple sentence like this also can lead thinking and belief onto a negative path. In Japanese culture, people, especially the older generation, tend to ask the following phrase, “*Oyaseni-narimashita-ka?*” as part of the greeting between people who know each other. It is an expression of caring and friendship by letting the other person know “I am thinking and watching over you”. When I hear it, I know they are trying to be nice to me, but it still gets to me every time. Even though I have repeatedly said to my father that I do not like my looks to be commented upon, and he seems to understand it at the time, still, every time we meet, once or twice a year, he comments on my appearance. He seems to have forgotten my request. However, I see now that he is simply trying to say something nice to me as a father. Looking back, I see that he is trying to be empathic, but still, I feel he fails. There are at least two plausible reasons for that: one is that he simply does not affect his behaviour according to the information I give him, or the second is that I was unable to see things from his perspective, for example, trying to see that he is perhaps more bound by cultural codes than by any personal information I share with him. As a consequence, neither of us was able to let the empathy flow. In another case, while I was filming, a member of

the cancer support group said to me, “Have you put on some weight?” When viewing the tape, I see that I took the comment joyfully, although people would usually take this as an insult. For me, I felt I was being assured of my sense of health.

If these mini-liminalities which I describe as one’s negative interpretation of one’s own body, are not isolated entities but parts of bigger liminalities within a continuous liminality, we can think of the phases set up by regular health check-ups as the bigger liminalities. The reason is that patients would not know whether their interpretations about symptoms were right or wrong until they meet with their oncologist and have some medical tests. When my oncologist found no sign of cancer return, I would come out with a great relief, not from his office, but from the bigger liminality. I could go on peacefully for some time, but then, as the time for the next appointment approached, I would get anxious again, and become uncertain about my bodily symptoms or reactions from people. No wonder many have thought about being a cancer patient as being the prisoner who is given a life sentence by the oncologist. I would say that Kurosawa’s *Ikiru* (1952) is one of the earlier models for this kind of view. Indeed, Stoller also used the term “prison” once in *Stranger in the Village of the Sick* (2004, p. 192). However, the word is not used in his later works related to cancer. I imagine he came to realise it as an unproductive way of further exploring the essential theme of how to live a good life while in remission. I interpret his use of the word ‘prison’ as his expression of the frustration of losing control of his own sense of health, his life situation, and perhaps even his destiny as only medical experts could know about the patients’ disease and save their lives.

But it is worth considering what it does to cancer patients and their sense of understanding about themselves and those close to them if one internalises this kind of negative worldview in continuous liminality for a long period of time. For instance, I recall Abe-san, an elderly man in his 70’s who looks like one of the *samurais* from Kurosawa’s films. He was always wearing *samue*, the work outfit of a monk. I met him at a cancer support group organised at the hospital. He seemed to like to come to the group because he was the only person who had attended all the regular meetings, unless he had a check-up that day. At his age, people usually join various hobby and



activity groups, but he said to me that he was not interested in any of those. I recognised that he talked about his cancer experience as if it happened yesterday, although his treatment was around thirty years ago. One day I heard him give a little speech to the others:

“This is what I always say to other cancer patients. We have all received a death sentence. We don’t know how many years we’ve still got. I’d like to remind you that cancer is the same as an execution. Doctors declare one as ‘cured’ when five years have passed, but I’ve seen some people getting a relapse even after 10 years. So, I wonder, how many years does it actually take to be really declared as cured, for sure?”

It was a small shock for me to hear that the idea of “cancer equals death” followed him like a shadow over the past 30 years. This was something that was considered true at the time of Kurosawa, or for me back in the US when I knew little about cancer treatment. Although he had crossed what I consider the “safe” zone (10 years) a long, long time ago, he still seemed to feel unsafe because he could not be assured by biomedicine. At this point Dr. Kato, who runs the support group, stepped in and gently said, “I don’t think this is entirely right”. This is a rare intervention by him since he tends to let his participants enjoy conversation by themselves. I suppose Abe-san’s speech could be misleading, especially for those who had recently been diagnosed. They are already overwhelmed and want to keep their motivation to survive, not passively wait for the final day to come. But I do not think Abe-san was trying to make them scared, he was rather trying to teach them what it had been like for him to live all those years. What I learned from him is that fear of cancer recurrence could go on even for three decades. He demonstrated that he is not simply living in the minimalities, but in a continuous liminality, and he never comes out of it.

By looking at this episode once again after considering Stoller’s story, there is an opportunity for me to think again about life in continuous liminality. If one cannot get out of continuous liminality, how should one look at it? It must be possible to change his or her own perception from within, to turn the image of the scenery in continuous liminality into something a little more comfortable. But how? As I started to ask

myself this question, I realised that a start to this answer would have to be to listen, which is a way to handle it mindfully, in line with Jon Kabat-Zinn (2013). When I started to listen, or was able to start to listen, it had to relate both to myself, including all the scary things I was thinking and feeling, and to what others said and felt. Then the moment I learned to trust in both, the liminality became more like a sphere I accepted instead of something which controlled me. Could this be part of the answer? And if so, what elements were part of getting back some control?

### *3.2 How can one go on with Life through Continuous Liminality?*

When I considered Stoller's condition – he had been trapped in continuous liminality for 10 years (at the time of our encounter) - I did not get the impression he was “bitter and resentful” (2004, p. 190) or overly confident and courageous, or represented by the image of the cancer survivor as hero. How was he able to maintain this attitude of being generous, caring, and friendly? I will trace some of Stoller's teachings in his text, but first I would like to explore from my own valuable experience of meeting Stoller in person.

It took a while for me to think through his last phrase (“I think of it every day. It's always here”) and the image of a mask evoked by his gesture. As I think more about it, he is disclosing a deep knowledge, like a trained scholar and Songhay sorcerer who has experienced a serious illness like cancer, and who has now been in remission for a decade. Gesture, according to David McNeill (1992, pp. 1-2), a leading figure in the field of gesture study, is not merely an “additional” feature of the speaker's speech, but gesture itself expresses parts of the speaker's thoughts. He argues that the speaker's thoughts and gestures are closely interrelated, and that people express their meanings both through speech and gesture, since each of the two “co-express” different dimension of the speaker's thoughts. Furthermore, gesture exhibits imagery that is available for the interlocutor to interpret. This means I should consider both the imagery that Stoller is trying to display through his gestures and the meaning of the images I read from them. In this sense, McNeill (1992) argues that paying attention to the role of gestures in a person's speech would open a “new dimension of seeing, a new dimension of mind...which lay hidden” (ibid, pp. 1-2). When I continue to explore this line of thinking, I start to see things I did not previously understand about his gestures.

For instance, Stoller raised his hand when he said the second part of the utterance (“It’s always here”). His hand visually demonstrated his thoughts about his cancer, as if the thoughts were right in front of his face, like a fog constantly reminding him of the liminality. However, as his interlocutor who witnessed the gesture while facing him, what I saw was his hand covering his face, as if he was wearing a mask. It highlights a potential barrier for empathy, both giving and receiving, during the conversation. Even more so, since I was also wearing a cancer mask as I have similar concerns to Stoller, it influences the flow of empathy between cancer patients. I could extend this view further to include carers who equally worry about the fear of cancer relapse (Simard et al., 2013, p. 300). I start to feel more emotional pain when I consider Watanabe’s communication with his doctor in Kurosawa’s film (see Chapter 1.1). The doctor refused to try to see the face beneath Watanabe’s mask, and Watanabe goes around the city wearing his mask, spending the rest of his time without anyone ever seeing his true face. His emotional pain and sorrow are left untouched. It makes me wonder how destructive it must be for Watanabe and those afflicted by cancer to live a life where nobody understands the face beneath the mask. It enhances the feeling of being alone and isolated, and the person is dominated by continuous liminality to a greater degree. Thus, the mask symbolises in some ways the border of “continuous liminality”. One may argue that this mask, then, lies like a potential barrier to empathy both in the sense of giving and receiving. It is like a veil between the patient and those around, and this veil can cause psychological pain, allowing the patient to be dominated by his or her liminality to a greater degree. Seeing it like this, perhaps the mask symbolises being in between – demonstrating the border where either the liminality grows or the person is able to let go of it to some extent. How does Stoller deal with this?

As I think more about his gesture, I realise how Stoller, in a powerful way, actually demonstrated his letting go of his thoughts about cancer and the mask he was wearing. For instance, he was not looking at his own hand, but was looking me in the eye between his fingers. His gesture seemed to say that, although his cancer awareness (as a hand) blocked a major part of his perception, he still chooses to look at life through its open space (between the fingers). He chooses to focus on the person interacting

with him in the moment, rather than being occupied by ruminating on thoughts in his own mind. Also, conversely, by focusing on the person in front of him, the awareness of the mask may be eased. This may be the moment when the view within continuous liminality has the possibility to be changed. This is a powerful message that was not spoken but shown through a gesture, and its powerful meaning comes to surface through reflection and exploration over time. However, I could easily have missed this important message if I had not paid attention to the role of his body during our communication, I would have missed that he was actually trying to show me his attitude towards life in a more meaningful way. Stoller's message also left me with three important questions related to the idea of empathy which I knew I would like to explore further in my PhD fieldwork and later in writing: how do you hear a message that is not spoken? and how do you understand suffering that is not visible?

When I was reading Stoller's recent work, *Yaya's Story* (2013), I started to see his generous attitude towards me as probably one of the many occasions in which he follows his own, what he calls, "greatest obligation"; where he offers generous help and guidance for his pupils and younger generations. In line with writing books and articles that are accessible and meaningful for audiences beyond academia, he finds it crucial:

to mentor as many students and junior colleagues as I could – as a way of meeting the greatest obligation of the (Songhay) specialist: to pass on what she or he has learned to the next generation (ibid, p.115).

I found *Yaya's Story* especially inspirational when I considered my own path in the life of continuous liminality. It seems to express Stoller's shift in his interest in the world of cancer, where he starts to explore his experiences with others who also suffer from cancer. There is a scene in which Stoller tries to start a conversation with his Nigerian friend Yaya. Stoller has learned that Yaya has been treated for cancer:

We looked at each other but said nothing. Although our relationship had spanned almost ten years, it was as if that was the first time we truly saw each other. For me it was a look of mutual recognition and

mutual resignation – cancer had now touched both of our lives. It was time to talk (ibid, p. 121).

Stoller then starts their conversation, a kind of talk that is difficult for both the speaker and the listener, but Stoller continues to listen attentively to his old friend. After this episode, Stoller continued to follow up on his friend's cancer journey for a long time until Yaya passed away. There were times when Yaya was not willing to respond to Stoller's help, but Stoller continued to offer it. It must have required a great sense of patience and endurance, and also respect and trust in Yaya as well as in himself. What I see is that this episode seems to be the reply to his own question, which he raised thirteen years earlier in *Stranger in the Village of the Sick: A Memoir of Cancer, Sorcery, and Healing*:

How do you confront a life that cancer has complicated and perhaps shortened? Once in remission, some cancer patients become bitter and resentful. Others try to conquer their adversary (2004, p. 190).

It seems to me that Stoller has continued along the difficult path of “between” the village of the sick and the village of the healthy, just like his Songhay mentor of sorcery, Adamu Jenitongo, was between villages, belonging to neither of them. When Stoller met his friend Yaya again, he used his own cancer experience as a way to attend to the concerns of his old friend. From the way he generously related to people including myself, I could see his *ikizama*; his respectable attitude toward his own life as a person and as an anthropologist. How could I make good use of this *sempai*'s guidance, which I learned from witnessing his *ikizama*? It was time to ask myself, “What is my attitude toward my life and those around me when living in continuous liminality?” I too wanted to look at people through my own cancer mask without being coloured by my ongoing health concerns.

### 3.3 Visiting the “Others” in the Shadow of the Cancer Patient

When I consider my own case, I recognise that there was a gradual, but critical, change in the way my research interest shifted from the illness experience of cancer patients to those considered carers, such as families and bereaved families.

As a person who has experienced cancer twice, and who has come to know other survivors in the cancer support group, I was amazed to discover how seldom I heard other survivors tell stories of families afflicted by cancer, and even more so of bereaved families. Why did I not hear their stories? At first, I thought this tendency was specific to Japan, but then I noticed the same theme occurring in Norway, as I have a Norwegian wife and family. Also, I came to realise a similar tendency in autobiographic works focusing on cancer (including tumours), such as the ones of Paul Stoller (see, 2004; 2009a; 2009b; 2012; 2013), Arthur Frank (1995) and Robert Murphy (1987). For instance, the descriptions of their families are very limited compared to that of their own experiences, although they expressed great appreciation to their family members for their support and understanding. From their descriptions alone, I had difficulty understanding their families’ experiences and feelings, and how they tried to listen to *their* emotionally sensitive concerns.

When I consider my relationship with my own family, listening attentively to the experiences of someone so close is extremely difficult, perhaps more so than writing reflectively about my own experiences. This is so especially because some of their suffering is not caused simply by how they witnessed me suffer from cancer, but how I caused them suffering by being in a bad mood and easily becoming frustrated and angry. To be honest, I have said things that I greatly regret, not once but on many occasions. Even further, I would say there were some emotional wounds I was not even aware of. I am not sure if I have enough courage to open the door to our painful (and sometimes shameful) memories by turning them into ethnographic research,

treating them as “interesting data” and then exporting them as an ethnographic text. I am not sure if I can ever take an objective stand when treating these private and emotionally sensitive matters, and even if I could, it would probably take a lot of time to come to terms with them. At the same time, such research would have direct bearing on my everyday relationship with my family, now and in the future. In fact, I have tried to include some experiences related to my family, but it has been overwhelming for me to uncover events in our collective memories that are intertwined with our suffering, emotional pain, unspoken dilemmas, fear, anger, and sorrow.

What I am able to say something about stems from being a person who has directly experienced cancer. After all, I was the one who suffered physically from the treatment and psychologically from the fact I have a deadly disease inside my body. They did not get sets of hard chemo in their veins or radiation on their necks. They did not battle with nausea, fatigue, or tremendous burning sensations of pain whenever I tried to swallow. But, I also know that they were witnessing all of this. In other words, what I do not know is how it is for them to witness me seriously suffer. Studies have shown that witnessing loved ones suffer produces a strong sense of helplessness. How can I then understand them?

“Under the shadow of the patient” is my favourite phrase, and represents the issue I am trying to articulate in this section. It is the difficulty of having open communication between patients and their family members about the experiences of cancer, and to find a flow of empathy that is so crucial for both. I heard this comment from a Norwegian doctor at the rehabilitation centre that my wife and I attended when trying to re-establish our lives after cancer. We had a chance to talk to the doctor, and he asked about the experiences of my wife during my treatment in Norway. She honestly told him it was difficult for her to be with me, since I was emotionally unstable. The doctor kindly told her that she was not the only person to disclose such an honest opinion, and then he used this phrase to explain how often the families of cancer patients were not given enough emotional support during cancer treatment in Norway. While patients are in the “spotlight” of a health professional’s attention, families and bereaved families often are not. They are under the shadow of the patient. Indeed,



although an increasing number of studies have shown that families and bereaved families worry and feel depressed (see for instance Sharpe et al., 2005; Glajchen, 2003), the health sector lacks the resources and time to provide care for them. This is especially true in Japan, where there is an ongoing budget cut in health services due to an overall decline in the health care system (Fujiwara et al., 2015). For instance, at the time of my fieldwork in 2012-2013, as far as I was aware, there was only one support group in Shizuoka and Kyoto together for families and bereaved families. In this sense, patients have much greater possibilities to seek emotional care compared to families and bereaved families.

Another angle when it comes to the metaphor of the patient's shadow, is how those who are in the spotlight often find it difficult to fully understand what it is like for their loved ones to be in the shadow. From one perspective, the story the Norwegian doctor told us is a widely and experientially observed phenomenon, and when I participated in the support group in Japan, I noticed how little the group participants talked about their families in their narratives. This could simply be an expression of feeling too shy or formal to openly express appreciation toward their partners in front of others, but I still found it strange that hardly anything was said about the role their families played in their cancer narratives. In the case of the elderly man Abe-san, who claimed that his life with cancer had been a prison cell for thirty years (see Section 3.1), where were the stories of his wife and children? How did they survive his cancer story? Did he not see them in the shadow? I even start to wonder if the self-centred narrative, *my* story, may enhance the feeling of being trapped in continuous liminality. According to Kabat-Zinn (2013), there is a problem with the idea of telling and retelling self-centred narratives about one's illness experiences. It just reinforces the way the story is being told by repeating what he already knows about himself, his cancer experience, and the world:

Often our thoughts build themselves into extensive narratives, stories we tell ourselves about the world, about others, about ourselves, and about the past and future. Still, when you really examine them by bringing mindfulness to the entire process of thinking and to our emotional lives, a lot of our thoughts are inaccurate, at best only partially true. Many are simply not true at all, although we invariably

think they are. This can create huge problems for us, generating certain patterns of believing and behaving in which we can get caught for many, many years. It is very easy to be blind to the ways in which our thoughts create our reality (p. 243).

When I think about it, in some ways, my shift in focus started to take place as I became more open to receiving constructive comments about my own “patient-centred-focus” from someone I could trust (e.g. the counsellor, Hedvig, my family and friends from the cancer groups). I recall one good example of this.

After I made *Ippo Ippo* (2010), the film for my master’s thesis, I had the chance to screen the film to members of Ippo Ippo. Most of the feedback was positive. They seemed to like the film’s narrative – closely following Marsha-san and her challenge of participating in the Mt. Fuji event for the first time. It could be that some of them were polite and stopped themselves from expressing critical comments to avoid hurting not only my feelings, but also Marsha-san’s. On the way out of the screening, many group members greeted me with more personal comments, and I felt rewarded. But there was one person who gave me a constructive comment, which nobody else did. That was Matsumoto-san, who lost his young daughter from aggressive cancer 10 years before. In many ways, he was the minority in our group, carrying with him the status of bereaved family member among the remainder who, like myself, were all cancer survivors. I have always liked him as he is a very friendly person.

Matsumoto-san told me excitedly, “Wake-chan, it was good! But I wish I could have seen more about how her family was doing while Marsha-san was climbing up Mt. Fuji. They too must be very worried.” It did not make me angry in any way; I was simply caught by his comment. It was not because I did not think of Marsha-san’s family. In fact, I believed I was conscious about the relationship between her and her husband, and how they both came to terms with the illness experiences by respecting the boundaries of each other’s worlds (represented by Marsha-san’s cancer support group as the “world of illness”, and her husband’s tennis as the “world of health” (see Section 5.2). I was hoping that both our filming experience and the actual film, *Ippo Ippo*, would give them an occasion to glimpse each other’s worlds, which they

otherwise only had a limited chance of seeing. However, what Matsumoto-san was pointing to was that I had taken for granted that I would follow Marsha-san's side rather than her husband's. Indeed, I could have made the same film by following her husband waiting for her to come back from her climb to the top of Mt. Fuji. He might for instance try not to show that he worries about her, while at the same time frequently checking his phone to see if he had any messages from her, stating that she had safely arrived. That could well be it. However, I never once dreamed that I could make such a film, because my mind was already set before making the film, my interest was strongly coloured by my own illness experiences. Matsumoto-san caught my shadow.

It shows that I should have been more aware of the current medical discourse in general, where families and bereaved families in Japan often are treated as “secondary level patients” (*daini-no-kanja* in Japanese), like Okamoto-san himself mentioned in the film *To the Last Drop* (2016). In the cancer service, helping families is secondary to helping the patients. In many cases I know of, hardly any help was available for family members unless they actively sought a support group. As mentioned, in Kyoto, I only knew of one support group for families and bereaved families, while there were at least five groups for cancer survivors. In this context, it is less likely for me or other survivors to know about the world of those who are in the shadow. This episode highlights how my perception and interest was strongly shaped by current discourse and practices of the cancer service in biomedicine.

Therefore, for my PhD fieldwork I decided to visit families and bereaved families, the world of those who are in the shadows of the cancer patients. I met Okamoto-san, the lead character in my new film, *To the Last Drop* (Wake, 2016) in the support group for families and bereaved families called Furatto (ふらっと), in Kyoto. He was a husband whose wife had been fighting cancer for the past six years. I still recall how Okamoto-san talked about his experiences when I first attended a group meeting. He said to the other members, “for us as a family (where a family member has cancer), it has been like we are on a small ship in a storm, not knowing where we are heading, but we are doing our best to endure in this situation”. I was quite amazed at how

radically different the families spoke compared to cancer survivors. If I had heard an equivalent expression in the cancer support group for survivors, I would probably have heard something like, “I feel like I am alone in my small ship, trying to steer in the storm, not knowing where I am headed”. I soon became a friend of Okamoto-san’s as we share the same great passion for tea making. Occasionally he would express how patients and families are fundamentally unable to understand each other’s suffering. There was a time when I felt a little hurt by his comment, although I did not give up getting to know him. His way of thinking has helped me see more clearly how separate one can be in the midst of uncertainty and pain, acknowledging that such a feeling is out there between the cancer patient and his family. Stoller described something similar to what Okamoto-san expressed, that something either unites us or separates us. When Stoller (2013, p. 121) met with his long-term friend Yaya after some time, he described that “it was as if that was the first time we truly saw each other. For me it was a look of mutual recognition and mutual resignation – cancer had now touched both of our lives”. Although I agree that cancer patients share something the family members do not, and vice versa, I have still learnt that this gap can become insignificantly small if one simply focuses more on what goes on in the shadow. For Okamoto-san, this gap was still very big. Nevertheless, we somehow bonded and became good friends.

The two of us each had our unique role in the group - he had his tea and I had my filming. While I was filming him, we talked a lot about how we could shape up his tea service in a more elegant and sophisticated way. When thinking back, he certainly liked that there was someone else who showed a great interest in his tea making, and was present while he was making it. If I had not been there, he would be alone in the tea making room, while everyone else in the group was talking and listening to each other. Serving tea might be his way of caring and showing concern for other members, but his devotion to the perfect cup would make him miss the possibility of engaging in conversation with the others, and thus engage in empathic interactions. In the next chapter, I will closely analyse a dilemma in which Okamoto-san disclosed the bad news about his wife’s cancer and walked out of the room for his tea service. I

happened to be the only person who could go into the tea room with him. What was I supposed to do?

## *4. Chapter Four*

### *A Visitor in the World of Shadow of the Cancer Patients*

#### *4.1 From Cancer Patient to Researcher*

Reflecting on my 13-year cancer journey – of wearing a cancer mask and a life of ongoing liminality and uncertainty – I see a certain trajectory that has shaped my interests and attitudes. It becomes evident that I went through some phases which furnished different perceptions and understandings of my various cancer experiences. It started with me being a silent sufferer who tried to perform the role of an American cancer hero. I tried to handle the enormity of a deadly disease on my own by being hyper-positive and suppressing all negative feelings. Armstrong's "hope kit" worked like "a performance-enhancing drug" for me, much like Armstrong himself, who was secretly taking drugs to stay a winner. In Armstrong's case, he was stripped of his title as a legendary cyclist. As for me, I had to learn the hard way to face these re-experienced feelings during life after treatment, when everything seemingly came back to order. During this time, talking helped me understand that these re-experienced emotions were expressions of my traumatic experience. Through psychological counselling, I tried to disclose my situation to a few select people, such as my girlfriend and family. Later on, during my initial fieldwork in Japan, people in the cancer support group were also informed. The group members helped me expand my worldview, and made me understand I was not alone when experiencing such a disease. They taught me the value of connection, sharing, and friendship with peers who have similar concerns and health issues. They were eager to have fun together, and I thought they had found a powerful way of creating a flow of empathy between themselves when living in continuous liminality. I felt it easier to disclose my cancer experiences to them, compared to disclosing them to people who have no cancer experience. However, after a critical comment about my documentary film *Ippo Ippo*,

which I received from a bereaved family member, I became more aware about “voices in silence”, such as the suffering of patients’ families and the bereaved families who do not receive the same qualitative emotional support in Japan, at least not at the time of my fieldworks (2009 - 2013).

The emerging issue I faced was “who is a sufferer in the cancer context?” I see that suffering is narrowly defined in medicine and in society, and care and attention are unequally distributed. I found myself having to answer the following question: Should I stay in the comfortable world of cancer patients? This would mean that I would continuously follow the trend and focus mainly on the lives of cancer patients. But now I know that the concerns of the carers are not well understood among cancer patients or the public. Like Paul Stoller, who redefined his core obligation as an anthropologist “to use her or his repertoire of skills to bear witness” (2004, p. 200), I also ended up redefining my position and decided to shift the focus of my fieldwork so as to listen to the stories of patients’ families and bereaved relatives. I wished to become an attentive listener in order to hear their experiences, even if I, as a former cancer patient, found it uncomfortable. These experiences might include, for instance, suffering because of the lack of empathy received from cancer patients, or what it was like for them to witness their loved ones die of cancer. I always had the following question in mind during my fieldwork: *how can I understand the suffering and concerns that people do not say in words, or even those things which cannot be expressed with words?*

## *4.2 The great Gap between the two Worlds of Cancer*

Visiting the world of those under the shadow of patients also presented many challenges and obstacles. As well as finding the focal point of my fieldwork, which would be difficult enough, I had to find a support group where I could meet patients' families and/or bereaved families who would also accept a researcher for their year-long fieldwork. When I looked online I found few such groups compared to support groups for cancer patients, and the ones I found were all in different prefectures from my previous research setting with Ippo Ippo. Since general support groups meet only one or twice a month, I worried that it might take a lot of time and expense to visit these groups from my hometown in order to establish a trustworthy relationship to get permission to attend the groups for my research. Under these conditions, I felt I had better make use of the network I already had based on my previous fieldwork. By chance, a member of Ippo Ippo knew Takeuchi-san, the organiser of the support group Furatto (the name implies that the group welcomes people in a friendly way) in Kyoto. The group accepts both cancer patients' families and bereaved families of cancer patients. I found Takeuchi-san's approach interesting because I had experienced how difficult it was for Ippo Ippo to run the meetings as they normally did when those with the status of family or bereaved family participated, simply because they had different concerns, and they wanted to talk and seek understanding about their own situations. For instance, some survivors found it difficult to be together with bereaved families because it reminded them of their own mortality. Likewise, I was also told that patient families show discomfort in meeting bereaved families for the same reason. But, I liked the approach of Takeuchi-san in that she did not dismiss the positive notion that patient families and bereaved families could help each other. In the same view, she also welcomed the cancer patients, but with the status of guests. I was glad that Takeuchi-san found me credible, most likely because I had kept my relationship with Ippo Ippo for the past three years and visited the group whenever I was on holiday in Japan. Though many experienced ethnographers may think this is common sense, I found it was not always the case for those who came to support groups with their



specific interests. For instance, TV directors, news reporters, researchers, and health professionals also come to support groups for their work and research projects. As I have seen myself in a few instances, they would come with a very friendly attitude towards the group during their project, but almost never showed up again once their projects were over (except from sending out nicely formatted appreciation emails or letters. Although I had always been careful to not come across as someone with a commercial interest, I still felt my ability to be an attentive listener could be improved in comparison to how I presented myself during the making of *Ippo Ippo*. After re-examining my own role as a filmmaker, especially how I filmed the sequence at the top of Mt. Fuji, it became evident to me that my filming method could easily hinder me as an attentive listener.



*Figure 12: Wake filming – with the big camera – the moment participants of Ippo Ippo reach the summit, 2009. Photo by Ohashi-san.*

In the photos of me standing behind the camera and filming the dramatic scene where everyone finally makes it to the top, see Figure 12, I seem to be too busy maintaining my role as a cameraman, mostly looking at them through a viewfinder or a monitor. I am present and occupying the space with them, but I am not sharing the moment of celebration with them, despite the fact that this was my first time on Mt. Fuji, as it was for everybody else in the group. There is no sense of face-to-face communication with them. Of course, this was not my intention, I simply had no awareness of how I used myself in relation to the others. I was focusing on the others through the camera lens, but I was not aware of my own behaviour with the camera.

My filming style at Mt. Fuji was not unique, but rather representative for many other filming occasions, such as during group meetings with Ippo Ippo. I often tried to have eye contact with people while filming or put the camera aside so they could see my face. However, the camera was still very present in the situation. I realised that for my

second fieldwork in Japan, I had to do it differently, I had to be present. I realised that using a mobile phone or a “small” camera could free up my face and body so that I could establish face-to-face communication during filming. Indeed, it made me feel that I could both attentively listen and, I believe, make the person in front of me feel as though they were being listened to. Figure 13 shows the “feedback screening” with Okamoto-san, in which the filmmaker shows recorded footage to the filmed person in order to seek his understanding, memories, associations, and ideas. Using a mobile phone, my approach becomes quite different to the more traditional approach of filmmaker Robert Gardner (see Figure 14).



*Figure 13: Wake's filming style using a smart phone, 2013. Photo: Shotaro Wake.*

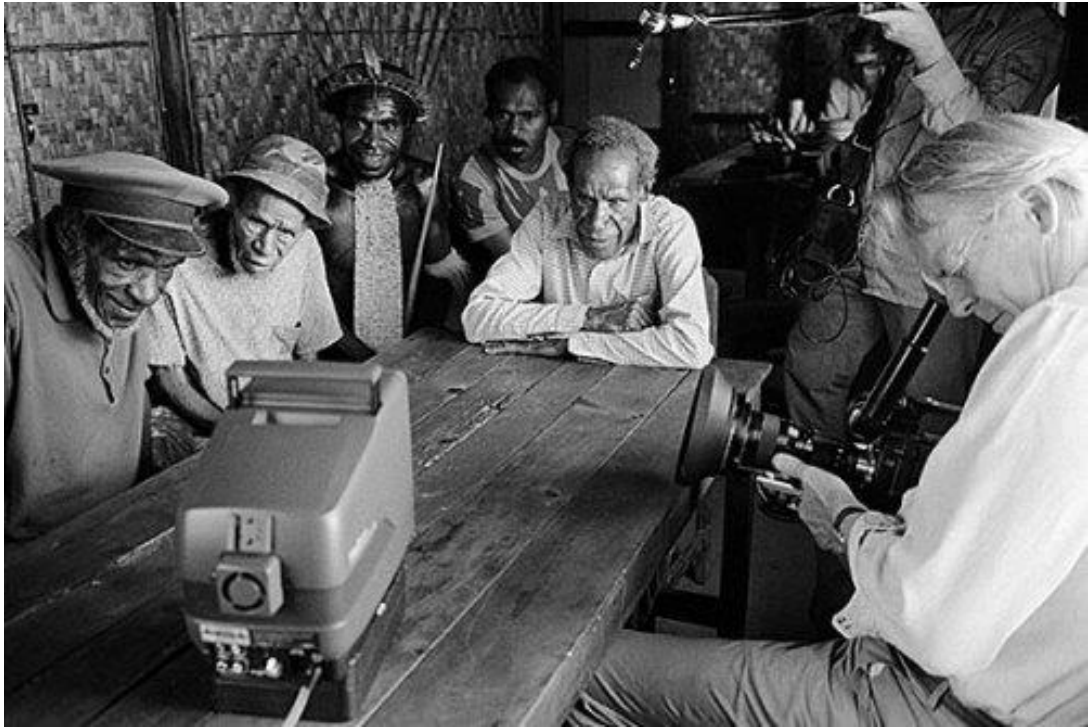


Figure 14: The filming style of Robert Gardner.<sup>5</sup>

Compared to the situation with Gardner, I seem quite casual in the way I hold the camera with only one hand and my legs crossed. I am facing Okamoto-san, the person I am listening to, and in fact there is eye contact between the two of us. It simply looks as though we are having a conversation about filming. In contrast, Gardner looks through the viewfinder of the camera to engage with people, their interactions, and the situation.

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<sup>5</sup> Photos: <http://news.harvard.edu/gazette/story/2013/10/an-ancient-tribe-and-change/>



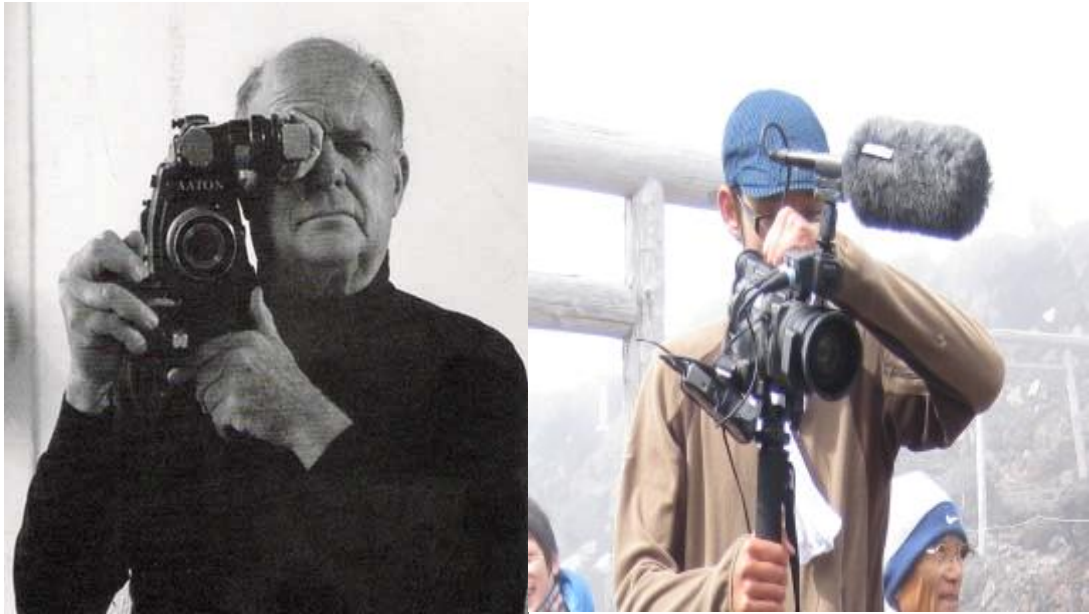


Figure 15: Looking through a viewfinder. Jean Rouch (right) and Wake (Left).<sup>6</sup>

As shown of Figure 15, if one of his subjects tried to talk to Gardner, the image he would see would be something similar to the photo of Jean Rouch and myself. Most likely, they would not get the sense of having a conversation with the director since there is literally no contact with the human eye, only with the camera eye. The way Gardner brings his head down to look into the viewfinder reminds me of the image of a medical examiner looking into the microscope to examine his subject, observing the cause of disease, so the subject and object are clearly divided. This occurs while many patients seek comfort from the doctor through interactive face-to-face conversation. Although Okamoto-san and I are engaged in face-to-face conversation, it was also obvious to Okamoto-san that I was filming while we were discussing the video footage shown on the PC, which I think is important. I was wearing a headset on my left ear, and Okamoto-san could see that my right ear was not covered, and that I could hear him. In addition, I had to check the monitor every now and then from the corner of my eye, but Okamoto-san could tell it was something I was paying attention to only for a brief moment. I became more visible as well as interactive and predictable compared to when I was filming at the top of Mt. Fuji. And importantly, I was able to listen. I could not agree more with the psychoanalyst Maureen Katz (AnthroPod,

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<sup>6</sup> Photos: <http://sensesofcinema.com/2010/great-directors/jean-rouch/>

2014) who, in a radio programme, reflected on her experience of working with torture victims: “Listening is a physical experience. It is not ever only an intellectual experience. It is not just hearing words”, and I could add; nor is it just about filming. The use of a small camera became a physical experience for me because my body was no longer hidden behind it. One way of creating space for listening and being present was therefore my choice of camera tool. And I wanted to bring a more conscious awareness of attentive listening to this new fieldwork; a consciousness that had been learned the hard way through my re-examination of myself at Mt. Fuji.

As part of establishing a connection with Takeuchi-san and others in Furatto, I used *Ippo Ippo* as an active communication tool. First, I gave Takeuchi-san a few copies of the DVD so that she and the others could watch it. Then I sought a time to receive her feedback at a café. I was glad that she picked up on my attitude as a filmmaker, the way I had established close friendships with people in the film, and the way I treated private and emotionally sensitive matters gently and carefully in the film. I imagine that through watching the film, Takeuchi-san could see a potential outcome for the new film that I would make based on Furatto’s group activities after my PhD fieldwork. In this sense, my previous fieldwork and filmmaking experience, and my status as a researcher who himself had had cancer, all helped me to participate in the new group, in a new prefectural area. I got permission to attend Furatto’s group meeting the month after coming back to Japan.

Although I got started right away, I did not feel as though I had enough time with Furatto, since the group meetings took place only once a month. I was afraid a few months would just disappear if I was only attending the group’s monthly meetings, and then having to wait until people started to recognise my face. I knew that I had to approach people, including meeting them outside of the group setting. However, I had already planned not to start filming until I had developed good relationships with people. Trying to film without having trustworthy relationships could be seen as being forceful, demanding, and impatient, since such an attitude would go against both the cultural and the group’s values and practices. I followed my plan, although I actually felt I was in a hurry and wished I could start filming as soon as possible. Through over

a decade of filmmaking and study, I have learned that the most difficult task is capturing how people's ideas, attitudes, conditions, and relationships change over time. To do so, a filmmaker has to be situated with the camera when the moments of change unfold themselves. The filmmaker does not know when these changes will come, but it increases their chances of catching them on film if the filmmaker spends more time with people during filming. No wonder that leading documentary filmmakers often spend many years on their film projects. However, I had only one year to achieve a similar effect. Still I focused on first building trust, which required time and so even after I was permitted to attend Furatto's monthly meetings, I did not film anything for the first three months. I attended the meetings in the same condition as other participants by sitting, listening, and trying to participate in group conversation. I tried to position myself through making good use of my role as a former cancer patient before taking on my role as a researcher/filmmaker.

When I started joining the meetings, it made me understand how different the world of patients is compared to the world of those who live under the shadow of the patients. In general, people did not treat me differently. They were polite, kind, and friendly to me in the same way they were to each other, just as I experienced in Ippo Ippo. Moreover, in meetings in both groups, there are moments when people express intense feelings of frustration, anger, and sadness, as well as positive feelings of encouragement and some laughs. But, the deep grief over losing someone so close came out more often in the group Furatto. It touched me deeply, and in a painful way, when I witnessed an elderly woman, Miwa-san (who took part in the film *To the Last Drop*, 2016), crying for her lost husband. Since I have had some periods myself when I was seriously worried about losing my life, listening to the sorrow of Miwa-san and other widows in the group made me feel as though I was getting a glimpse of how it would be for my family to weep over my death. Ontologically, this is impossible, but it gave me a rare occasion to think, feel, and imagine what the lives of those close to me would be like after I had gone.

I was then surprised to see how Miwa-san, who was in tears, could then cheerfully laugh in the next moment, by saying something comical or hearing others'

encouraging comments, as is shown in the film. It took a while for me to grasp that her vivid oscillation between the two emotions is, in fact, due to the presence of other participants who show their efforts to empathically listen to her story and respond to her in a sensitive way. It was as though strong forces of past and present interplayed within Miwa-san – talking and listening elicited the memory of her husband, but she also seemed to enjoy being together with others in the here and now. I recall that Miwa-san often complained about how rarely she would have occasion to talk to someone in her everyday life. Losing her husband also took away most of her opportunities to talk to people on a daily basis. Numerous things that she would have said to her husband now turned into a monologue in silence.

It was puzzling to witness all these emotions being expressed, and I found myself in a situation where I both had to deal with my own emotional reactions to what it is like to be under the shadow of the patient, and also how to approach the group members who were in the midst of these strong feelings. I found it interesting that I did not feel anxious witnessing Miwa-san's deep grief. Actually, it made me feel I also wanted to encourage her, although I did not know how. Still I wished I could let her know that her talk touched my heart. But, as I will discuss in the following section, I had not really foreseen the laden atmosphere that would meet me, especially how my cancer status actually restricted rather than broadened my position as an attentive listener in the group. I had to juggle between my multiple roles as a cancer patient, a researcher, a filmmaker, and a Japanese man who had to follow certain cultural and social norms and etiquettes.



### 4.3 Limits to my Expression of *Kyokan* Empathy

The gap between the two worlds became increasingly pressing for me when I tried to engage in group conversations about cancer. I did not know how to properly respond to their stories since I had never lost a family member to cancer. I felt empathic towards their stories, but, due to the social norms I had to follow, I did not feel I could directly express my feelings without concern about how they would be perceived by others.

I felt as though my cancer status limited my choices in verbally expressing my empathy. For instance, the things I was able to say with more ease to other cancer patients in Ippo Ippo, could here be interpreted as inappropriate or careless in the eyes of families and bereaved families. It simply did not feel right to say things like “*sodesu-yone*”. This is a highly useful phrase which demonstrates “active listening, interest, and understanding and function[s] as reinforcing cues that facilitate the addressor’s flow of speech” (Iizuka 1993, p. 207). But I had to be careful when using it with the participants of Furatto because I was aware that some of them might think: “how can he understand since he has never lost anyone in his family to cancer?” They might see me as a careless person. It would probably be more appropriate for me to use the alternative but similar phrase “*sodesu-ka*”. This is the phrase that visitors (e.g. TV directors and researchers) would use to express their understanding. However, although the two phrases may look alike in the eye of a non-Japanese speaker, the difference is essential to me. “*Sodesu-ka*” is more like an expression of understanding based on highlighting the difference in position, rather than one of being equal. However, the feeling of not being able to come as an equal to these people presented a problem for me when trying to express my *kyokan* empathy because, according to Lebra (2004), “*kyòkan* empathy is supposed to take place between equals”. She writes that “the word *kyòkan* [is] favored to indicate a mutual, symmetric communion between self and other, as opposed to a vertical relationship” (p. 209). I found that this stress on the *position* between people in *kyokan* empathy differs from the notion of Western empathy where the stress is on *perspective*. For instance, Hollan (2008)

starts his paper on empathy by referring to the definition of empathy by the medical doctor and professor Jodi Halpern: “empathy [is] a first-person-like, *experiential* understanding of another person’s perspective” (p. 475). From this view, to take someone else’s perspective, one has put oneself in someone else’s shoes, so to speak. But in the Japanese context, the relationship starts from the way people actively highlight the *differences* in each other’s positions in a vertical sense by making their social status (occupation, age, gender) *explicit*. Using honorific language is a sensitive way to explore differences between people and create a relationship in the vertical sense. For instance, when I deliberately address someone as a *sempai*, I know that I am establishing a connection between myself and the person since I am taking the lower position as the *kohai*, a protégé. It may be impolite in Japan to claim that one person can take another’s perspective. That is perhaps why the group organisers often ask only the surname and cancer status for participants during the meetings so that their social status remains unclear, and participants may feel freer to address each other from equal positioning during the meetings.

Based on my findings in my study of empathy in the Japanese cancer context, I would like to add one point to the discussion of empathy led by Hollan and Throop (2008). As I have mentioned elsewhere, they argue that the study of empathy needs to focus on the role of others (the empathised) during the empathic process between people. However, a researcher in the Japanese context needs to consider the role of positioning in social interactions. Nevertheless, Lebra uses an example to remind us that there appears to be a potential social limit when it comes to empathic positioning. Consider the following example described by Lebra, when the empress Michiko expresses her *kyokan* empathy to the Japanese citizens:

Recent news (7/10/01) released her carefully worded response to the question of what she keeps in mind (with *kizukai*) when meeting with people. She said, “Everyone is living with a sense of shame because of his or her weakness. It would be desirable if we recognize one another’s [otagai] such feelings, endearing and encouraging one another [otagai].” Although the language is vague, her repetition of *otagai* suggests the empress’s wish to emphasize mutual resonance in empathy, thereby positioning herself on an equal footing with fellow

humans. Through equalization, the traditional sentiment of empathy is not wiped out but rather becomes, I think, more diffuse (2004, p. 209).

The empress expresses her wish to position herself (by coming down) on an equal footing as her citizens, which many people accepted. I suspect it would be almost impossible to move in the opposite direction. For instance, many Japanese people would find me extremely arrogant if I were to openly say I could understand the feelings of the empress. I can only say that I could sense or guess, *satsuru*, her feelings. This example shows how a higher social status has greater agency in terms of controlling the positioning in a relationship. In this sense, it is no coincidence that the Peer Support Programme highly stresses equal positioning as a ground rule, since experts know very well that social status between peer supporters and peers can easily prevent them from giving and receiving the kind of qualitative emotional support that is desirable. Yet, as will be described in Chapter 5, I could not give proper emotional support to Ohshima-san when I tried to disregard our social status. Equal positioning sounds nice, but it is difficult to suddenly disregard all other important social norms the Japanese live by. The group Furatto also emphasised equal relationships, but my cancer status seemed to counteract the possibility of establishing mutual relationships with the participants.

Besides the limitations I felt in verbal expressions of *kyokan* empathy, I also heard things that intimidated me. For instance, the group organisers told me how some widows had complained to them about cancer patients attending the meetings as guests. “Why are there cancer patients here in the meeting? I do not want to see cancer patients who are still alive!” (“*Ikiterukanja-wa-mitakunai*” in Japanese). I know they were not necessarily talking about me, but it made me even more self-conscious about my presence in the group, and how others might think about me as a former cancer patient. I felt unsure about the right or wrong thing to do as a listener at any given moment during the meetings. Indeed, maintaining my role as a passive listener was probably the safe thing for me to do, such as staying still without saying much while empathically mirroring their concerned looks, and nodding occasionally as the others did. I wanted to really get to know people and hopefully become good friends with

some of them, but I was not able to achieve this. This was the point where I had to modify my approach by moving the focus away from my cancer status. I decided to make use of my role as a researcher and filmmaker.

## 4.4 Working collaboratively as a Researcher and Filmmaker

After three months of attending the group meetings and being polite and friendly to everyone, I was given some recognition by the participants, so I approached the group organisers to ask if I could start filming the group meetings. I thought that by documenting the group activity in general instead of having a particular person in focus, and then showing what I had filmed afterwards, could be a soft way to establish my role as filmmaker. After the group meetings, I tried to set up a meeting with the group organisers, Takeuchi-san and Ohshima-san, and we watched the videotaped footage together at a café. This was the beginning of my active use of “feedback screening”, one of the popular methods used within visual ethnography today. This is a method I have admired since I first saw Jean Rouch’s and Edgar Morin’s documentary film *Chronique d'un été* (Chronicle of a Summer, 1961) as an undergraduate student of Film Studies. For Rouch, feedback screening should be based on “a principle of exchange” between a filmmaker and their subjects, which are necessary steps towards building a mutual understanding (Henley, 2010, p. 316). In my case, as a first step, through watching the footage together with the group organisers, I could ask them things that would otherwise not be possible during the meetings, as they were always busy facilitating. With the footage, I could ask more specifically about the participants, the group topics, and the way they organised the group. I found that they too seemed to find this occasion valuable. They reflectively discussed their own experiences, challenges and obstacles in facilitating. They looked quite carefully at the images to find meaning in people’s subtle expressions. They were also sensitive to the way people seemed to change their expressions, according to their moods. That made me realise they were quite careful about the way they facilitated the group meetings. They were sensitive to participants’ feelings and, in particular, they refrained from directly addressing people’s emotions, concerns and interests.

Through this process of filming the group in action and the feedback screening with the organisers, I became more conscious about Okamoto-san's tea service and his relationship to the group. The first time I showed the footage of Okamoto-san preparing tea for the other participants in the office kitchen, the two organisers showed great interest (see Figures 16 and 17).



*Figure 16: The two organisers of Furatto watching the video material of Okamoto-san on PC during the feedback screening, 2013. Photo by Shotaro Wake.*



*Figure 17: Okamoto-san preparing tea, 2013. Photo by Shotaro Wake.*

Since the tea tastes good, they understand that Okamoto-san must be putting in quite an effort in making “a great cup” as Takeuchi-san calls it. However, they had no idea to what level he dedicated himself to making the perfect tea. In addition, his whole ritual of making the tea was quite hidden as he always left the group meeting room. The fact that he left the room also meant that he was silently granted permission to leave the room during the group meetings. This is interesting since when I was sitting at the table like anyone else, I felt I even had to refrain from going to the bathroom because such an action might be seen as impolite, especially if someone was sharing a personal story. Leaving the room could in itself be read as an expression of my intentions and attitude as a person. It could, for instance, mean that I was not interested in listening to the current or next speaker. This sort of awkward situation was something I had to be careful to avoid. It reminded me of the simple but essential condition of support groups in general: people come to a support group to seek someone who is willing to listen to their emotionally sensitive concerns related to their cancer experience, but at the same time, they face the expectations of others who also want to be listened to by them. This means that if somebody wants to be understood by others, then in return he or she needs to listen just as attentively to the others. However, it was accepted that Okamoto-san left the room to prepare tea for everyone.

When I first joined the group, his tea service was not yet “official” as he had only made tea once or twice on special occasions. He and I did not meet due to his tea making, but through our cancer statuses. At the time, Okamoto-san was particularly clear about the idea that our differences in cancer status would hinder us in mutually understanding each other’s cancer experiences. He used to tell me things like, “after all, patients would not be able to understand the feelings of the families,” highlighting our different positions in the worlds of cancer, as though this was the definite condition in life. I felt uncomfortable hearing that my cancer status would prevent me from becoming a friend of his. However, I had to respect the fact that Okamoto-san was not too keen to talk about his private matters, not only to me but also to others.

It took me a while to notice why Okamoto-san insisted on highlighting our different cancer statuses in the group context. I realised his cancer status was important to him because it gave him the opportunity to connect with the majority of the participants, mostly widows, whom he would otherwise not so easily find a connection with. Though the group was open to both genders, he was often the only male participant with the status of family. In both Ippo Ippo, Furatto and other cancer groups I visited in Kyoto, middle to elderly women comprised the majority of the group. Based on the few men I met in the groups, they strongly followed the Japanese norms of how a man should behave, and they had not learned how to talk about emotionally-sensitive topics without coming out as and being seen as awkward, or appearing too intense. Even I, almost a generation younger, felt uncomfortable talking about emotionally personal topics in the cancer groups. “Men do not cry” or “Do not become emotional (like women)” was how I was brought up. In addition, another dimension was playing a role. According to Joy Hendry, “In general, it is felt to be imposing on people to reveal too much of one’s own feelings, and it is also something of an art, particular among women, to be able to anticipate or divine what lies behind a mask of polite expression” (1995, p. 65). Though I know some men who have great skill in sensing the feelings of another, I do not know many who are skilled at expressing this in the way women are able to in group conversation. Altogether, I believe this hindered a lot of men from joining cancer groups they could very well have needed.

The main reason Okamoto-san continued to come to the group was probably due to his friendship with the group organisers, and his wish to support their goals for creating a space of emotional support for families and bereaved families. Yet, at the time I started to visit the group, he did not seem to know how to make good relationships with the widows without relying on their common cancer status. I would have felt the same because it would be highly unlikely I would ever have met or connected with these widows in my everyday life in Japan if we were not connected through our cancer status. We have different lifestyles and different preferences when it comes to conversation. The main reason I decided not to use a widow as my protagonist was that if I did, I would not be able to follow her in her daily life, for example by visiting her casually in her house. There is something sensitive about a



man visiting the house of a widow. Neighbourhood gossip is still prominent in Japan, in particular in local communities, and could potentially socially discredit a woman. For instance, one widow told me that if she put on a little colourful makeup or dressed up, she could receive sarcastic remarks from her neighbours, as though she were interested in someone else now her partner was gone.

Although Okamoto-san behaved like most men, and was not revealing much about his emotional state, he still continued to show up at the group meetings, even though I noticed that making good relationships with the widows seemed difficult for him. He did not look happy sitting in the group meetings. He was, however, more at ease and relaxed both before and after the meetings. I imagine that he probably also found it hard to listen empathically to the stories of widows who had lost their husbands to cancer, while in his pressing life situation he was doing the very best not to lose his wife by encouraging her to continue with her cancer treatment. When thinking about it, he probably felt uncomfortable saying “*Sodesu-yone*” to the widows too, as I imagine that he probably did not know how they felt and did not want to know. It was puzzling to me that he kept coming to the group meetings. When I asked him, he told me that Furatto was the only group he could find in Kyoto that was for family members and bereaved family members. Since he got along well with the two organisers, he also wanted to help them run the group. During the feedback screening with the two organisers, they acknowledged that he seemed to be alone in the group and said they wished more family members would join so that Okamoto-san could find somebody who was in the same situation as he was. They also gave me the impression that Okamoto-san and I could become good friends.

Knowing more about the group dynamic, I started to think about how I could contribute so that Okamoto-san could have a better relationship with the others in the group. I especially thought about how to do so through filmmaking. Before coming to the group, I had the idea of organising a collaborative mini-film project. I was planning to seek participants who would be interested in making a short film to express things they were interested in, and I would help them edit their films. It was based on the method of collaborative ethnography (see Lassiter, 2005), where the

researcher and subjects come up with a mutual aim for investigation through doing creative work together. I thought this would be an empowering way to give control to the subjects, rather than the researcher controlling the outcome. However, I quickly grasped that this would not work in my research context. It was obvious to me that some people were too busy managing their lives to even think of taking on another task. Okamoto-san, for instance, has a demanding job which comes with night shifts, and then he is busy taking care of his wife and daughter and two dogs, as well as having his hobby, including the support group meetings. He would neither have the time nor energy to make a film in his spare time. Nor would he be able to edit and publish the work, even with my help. I found that a better approach would be to use my role as filmmaker and the task of filmmaking in an area Okamoto-san found interesting. The group organisers also showed great interest. This area was his tea service.

It is interesting that this became his way of reaching out to the group of women. Preparing tea is often considered a task for women in Japan, but by taking it on, he seemed to have found a way of moving beyond their cancer status and relate to them. From this perspective, the tea service gave Okamoto-san great potential to establish friendly relationships with the women through conversing over a cup of tea. Thus, I did not simply discover the potential of the tea service. Rather, Okamoto-san seemed to take the opportunity to actively establish his role as a helper to the group, so that he found an easier way to be with the others. Together, side-by-side, he and I became a team, working collaboratively to serve each other's interests. He wanted to create a sophisticated tea service, and I wanted to film it. Through this process, our relationships to the others might also change over time. In addition, I think the group organisers liked that everyone could enjoy a good cup of tea during the meetings, as well as giving Okamoto-san some space, which we all saw was more comfortable for him. Through working collaboratively with Okamoto-san, I gradually got to know him and eventually his family through the small glimpses he shared with me. He seemed uncomfortable when I asked about the condition of his wife, but he was happy to talk about his family teapot (see Figure 18) and how he had to treat it carefully so it did not break, all for the sake of his wife. I understood he had great concerns for her.



Figure 18: Okamoto-san's family Wedgwood teapot, 2013. Photo by Shotaro Wake.

Through working collaboratively, and without knowing it, Okamoto-san taught me a sensitive way of being with him which enabled me to show empathy in line with the Japanese context. I had struggled to express my empathy in a way he would not only recognise, but also accept. In the early phase of our relationship, when it was only based on cancer status, there was a time when I tried to challenge his idea of “the two worlds are separate.” As our friendship grew, we started to discuss this openly, but it did not mean he changed his viewpoint. Instead, our relationship became what we call *heiso*. Instead of trying to erase our differences or not acknowledging them, we walked side by side, accepting that he had his world, and I had mine (see Figure 19 below).



*Figure 19: Depicting the heiso relationship between Okamoto-san and Wake. Screenshot from To the Last Drop, 2016.*

I recall one particular occasion towards the end of my fieldwork. Okamoto-san, Takeuchi-san and I were discussing the potential communication issues between patients and families, when he said “I am sorry to say this in front of Wake-san, but I think families and patients cannot understand each other...” The beginning of the phrase showed he had consideration for my feelings. I noticed that there is the idea of respecting each other’s worlds as they are, rather than trying to bridge them. This is an idea I will take further in Chapter 5, where I will discuss the relationship between Marsha-san and Shimo-san.

Our working collaboratively went well on one level. He had started to make tea at every meeting and I went with him, filming. At the time, I did not fully understand the consequences of being omitted from the listening role – not only the consequences for me, but more importantly, for Okamoto-san. The group dynamic was built on reciprocity in listening, it was even seen as an obligation, and it was the main ingredient for growing trust and respect in the relationships. However, this new way of being in the group, intended to be good for everyone, created a new problem. As Okamoto-san tried to refine his tea service, it meant spending more time away from the group, time that was instead spent alone in the nearby kitchen. He could have two to three rounds of making tea during a meeting. In fact, at one point I realised that he

spent over half his time away from the group. This was to such a degree that he really did not know what went on in the group conversations. Since I had become his “chief assistant”, as Miwa-san among others cheerfully called me, I thought I could bridge the space for him by going back and forth between the two rooms to film part of his tea service and part of the group meeting. I did not question my own actions at this point because I believed things were going well. In the kitchen, Okamoto-san was eager to hear from me about what was going on in the meeting room, and he often gave me some comments, such as who would need most attention from the group on that day, and who should be paid close attention to. This sort of chatting in the kitchen, or Goffman’s “backstage” (1959), seemed to be comfortable for Okamoto-san, compared to having to listen patiently to the emotionally painful stories directly from the others. Also, after each meeting, almost every month, I invited him to the feedback screening where he got a chance to witness what went on in the group. In addition, he was further updated about the condition of each member by the organisers. However, I should have understood earlier that seeing a situation on a screen and being given information via us was not the same as attending the meetings. Okamoto-san seemed to develop the idea that his tea was a medium for communication. He said he could communicate with others through his tea service, although it did not always work out as he intended. In one sense, it was probably true that tea was his medium of communication, but those who received his tea seemed unaware of the fact that the tea was a communication tool. The film reveals some of this tension: he is concerned about how the others drink their tea as an expression of their appreciation, rather than using it as an opportunity to converse with them over the tea he had just served. This was reinforced by the fact that he was away during tea preparation, making it difficult for him to join the group conversation, even after the tea had been made. So, his pattern at each meeting would be to give a short update about his life during the introduction at the beginning, but then quickly leave the room to prepare the tea, and there was no time to listen or be listened to by the others. The consequences of him taking on this special role and me being his “chief assistant” came to a climax on the day he disclosed to everyone the recent bad news about his wife’s cancer relapse.

## *4.5 My Dilemma: Being an Attentive Listener*

I was stunned by the recent bad news of Okamoto-san's wife having a cancer relapse. Soon after, he left the group to go and make tea for everyone in the kitchen, as always. The rest of us were left behind with a heavy atmosphere in the room. People's faces looked darkened, and although the meeting went on as usual, everybody seemed to be very aware that in this meeting, Okamoto-san was the person who needed attention most of all. However, Okamoto-san's tea preparation hindered him from having any further opportunity to talk about his situation and being listened to by the others. I knew that the other members would have been more than willing to listen to him and support him, but he still chose to go on with his tea service as usual. I assume that in one way this was easier for him than to delve into an issue which was clearly very emotionally difficult. Indeed, carrying on as usual was something Okamoto-san told me was the most important strategy he had learned over his six years as a carer. He felt it was a remedy against the cancer disorder.

I knew I was the only person in a position that allowed me to follow him, and I wanted to let him know I was concerned about him and his family, though at the time I did not know what to say to him. I was afraid I might hurt his feelings. I also wondered why he had not told me the news beforehand. We had lunch together before coming to the meeting, and we fetched water from a local shrine for the tea. He had many chances to tell me, if he had wanted to, but for some reason he did not. In fact, I had not even noticed that he had such a big thing on his mind. He even looked joyful when we started to discuss which three books we would like to bring to a desert island. Instead of telling me the news, he decided to tell everybody at the meeting. I was therefore concerned that he perhaps did not have enough trust in me, and if so, would I make it worse if I came into the kitchen in such a situation? Before following him, I checked with Takeuchi-san whether she already knew about his wife since they are good friends, but she did not know either. She even added, "I wish I could ask him", a sentence that told me she felt it would be too much of an intrusion. This information was enough for me to set my mind on talking to Okamoto-san, though I still did not

know exactly how. As soon as he left the room, I had to carry on with my own special position and the responsibility that came with it.

I felt a lot of emotions during the talk with Okamoto-san, and even today I am not sure if I did the right thing. As far as I can recall, it all went so quick. In my memory our meeting in the kitchen stands out as very strong, as I experienced lots of different emotions while filming it. Afterwards I did not fully remember what went on, and I was glad I had captured the moment on film so that I could go back and review it carefully. In addition, watching the scene many times resulted in a process of “defamiliarization, alienation, or self-distancing” (Crapanzano, 2003, p. 4). I got access to visual details, such as the role of our bodies, both in the indirect and the direct communication we had in the kitchen. How spoken language and the body worked together to convey meaning were crucial points in my interpretation of what happened. Although my body is not visible on film, my choices of camerawork, movement and timing are all informative about what made the conversation move forward. I believe, though, that one important thing in the kitchen situation was the fact that in this fieldwork I had chosen to use a mobile phone as my camera. This meant that to Okamoto-san my body was visible, perhaps making it easier for him to talk with me, and in addition, I could pay full attention to him. However, as we were more visible to each other, I felt more naked compared to the time when I used a big camera at the top of Mt. Fuji. In addition, I felt especially naked due to the very emotional situation we were in.

The analysis of the sequence of Okamoto-san and me in the kitchen will show that our spontaneous and affective encounter seemed to carry our conversation beyond control. I felt as though I was losing my sense of control over how to handle the situation, and it also seems to be the case for Okamoto-san. By looking at the sequence and analysing it I want to focus on the dimensions of the act of listening attentively while filming. Below is a link to the sequence with Okamoto-san taken from my film *To the Last Drop*, which the following analysis is based on (00:41:31 – 00:49:15).

Here is a link to the film clip: [Kitchen scene with Okamoto-san](#)

Password: 5678



Figure 20: Kitchen scene with Okamoto-san, 2013<sup>7</sup>.

I came into the tea-making room unsure of what to do in this situation. I saw he was preparing tea like any other time. I saw that he noticed me coming in, but he quickly went back to doing his business. I came and stood at the opposite side of the wall, next to the kitchen table. As it is a tiny room, I found that this was the only place from which to be able to frame his preparations for making the tea. I did not want to start a conversation, as I did not know what sort of mood he was in. If this had taken place in an English-speaking context, there are some really good phrases like “how are you feeling?” or “is everything all right?” that one could use to explore his mood, but these phrases are not appropriate to use in Japanese. So I decided to wait. He too seemed to find it awkward, not having any conversation between us, but from the way he said “I forgot to buy milk,” it gave me a clue as to how disturbed he was by the news, not simply by sharing something difficult with everyone, but even before coming to the group. I had noticed that he tended to forget things (like the tea pot!) due to stress, and

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<sup>7</sup> All pictures with Okamoto-san in this chapter are screenshots from the film *To the Last Drop* (Wake, 2016).



forgetting the milk this time seemed like an expression of this. Only a week earlier at the café, he was talking eagerly to the group organiser and I about wanting to try to serve real milk for this occasion. Thus, it seemed that the right thing for me to say was something that would give him reassurance that tea without milk would be just as good for this occasion. This seemed to work quite well. From where I was standing, I could not easily see his face as he was turned away from me, looking for something in the basket behind him. I could wait of course until he came back to the kitchen table. But I felt I had to ask him the question that kept coming back to me. So, I gave up my position to sit down next to him. This was the first time I had ever taken on this position since I had begun to follow him into the tea-making room. It was an intuitive decision, and I did not think much about how it would let me film his tea preparations at the kitchen desk as well as the other position did.



*Figure 21: Kitchen scene with Okamoto-san, 2013.*

I asked him the pressing question I had in mind, “When was the hospital visit?” and that was my first step towards the things I wanted to ask him. I wanted to know how long he had been bearing something so enormous on his own. Based on his response, I was still not sure when exactly he had heard the news, but I saw that my question seemed to open up our conversation. He went on explaining things he had already told others in the meeting room a few minutes ago. Why? I guess he was probably

interested in knowing how I would respond to his story. Indeed, when he told the others in the meeting, he could not see me as I was filming him from behind.



Figure 22: Kitchen scene with Okamoto-san, 2013.

When I look closely at our interaction on the video, I notice that he seems to show a strong interest in my reaction to his story (00:42:51 – 00:43:53). For instance, he glances at my face at the end of almost every utterance within one minute of conversation. From the excerpt below it can be seen that he looked at me in 12 out of 14 utterances:

- Wake: When was that hospital visit?
- Okamoto-san: Let's see. It would have been ... Around ten days ago. (1)  
She went for her check-up. (no eye contact)  
But this time, in the ultrasound they could see some shadows. (2)  
Then on the new CT scan it was not only in her liver,  
but in her lung too. (3)  
They said, in a blood vessel (4) that goes to the liver. (\*5 starts →)  
So they're convinced it has spread. (5)  
And that's the story. (\*6 starts →)

Wake: And your wife knows it all. (6)

Okamoto-san: Oh, for sure. (7)  
 Actually, I heard it from her. (8)  
 Straight away they asked her to start chemo. (9)

Wake: Has she started?

Okamoto-san: Actually, not yet. (no eye contact)  
 She wants it scheduled from July onwards. (10)  
 She's due in hospital on the 1st and out on the  
5th. (11)  
 So she'll need a new port. (12)

During the conversation above, he looked at me almost all the time, which was a lot compared to our previous conversation about the milk, when we only looked at each other once! Especially he continuously looked at me while he was telling me that the doctors were considering that the cancer had spread (number 5 in our conversation above). In other words, he was carefully observing how I would react when he told me about the moment the new diagnosis was given to his wife. I was very aware that he was interested in my reaction to his bad news, and I wanted to tell him I was very concerned about him, his wife, and his daughter. I tried to keep the same attitude as when I came into the room, by not showing any sense of overreaction, fright or pity. I was particularly conscious about meeting his eye whenever he looked at me, and I waited until he looked away. Like many Japanese people, in normal conversations I feel I am in control of when to make eye contact or not, but in a serious situation such as this, if I had avoided eye contact, it might have given him a clue that I was disturbed by his news, and such a reaction might mean I was thinking his wife may not survive this time.

Okamoto-san's behaviour of frequently looking in the direction of the camera is something widely considered as breaking one of the ground rules in filmmaking. The rule is simply "do not look into a camera while filming!" This rule has been shaped by over 100 years of filmmaking, especially through fiction film. Subjects are supposed to act and perform naturally in front of the camera as though it was not present. Of course, avant-garde and documentary filmmakers and critics have seriously challenged this a universal ground rule, but I would argue that this rule has

become tacit knowledge, and people in the film industry also get to learn through being involved in filmmaking. To demonstrate my point, let me use a sequence from the movie trailer of Gardner's *Dead Birds Re-encountered – preview* (2013), a follow up of his film from 1963 *Dead Birds*. I have already discussed this sequence earlier, and it relates to when Gardner meets his old friend.

Click here to watch the video: [Dead Birds Re-encountered – preview](#)



Figure 23: Screenshot of Gardner's film *Dead Birds Re-encountered – preview*, 2013.



Figure 24: Screenshot of Gardner's film *Dead Birds Re-encountered – preview*, 2013.

There is a moment in which Gardner's friend is looking directly at the camera or, to be more precise, at the cameraman who is filming him through the viewfinder (see Figure 23). He quickly looks away (see Figure 24) and continues to hug (00:02:29). From the way he is looking into the viewfinder, his friend seems to instantly sense that the cameraman is still filming the situation, and this he takes as a cue to carry on with the performance. It is remarkable how quickly his friend adapts to the code of conduct after 28 years of not filming with Gardner.

This example allows me to highlight that Okamoto-san's frequent looking at me was not about breaking the ground rule. He was carrying on with an interaction style similar to his everyday life. It is because the camera did not block any face-to-face communication. Unlike Gardner's cameraman, he did not receive any cues from me to remind him that he should not look towards the camera. My concern was more to

focus on my own performance while listening and being sensitive to what he was saying. But how could I respond to him in an empathic way through my bodily gestures? It was not easy, and I became more uncertain about what to do in the situation as our conversation went on. This is partially highlighted in the next example from the way we had a moment of sustained eye contact, which created a strong tension.



Figure 25: Kitchen scene with Okamoto-san, 2013.

It did not feel right for me to take my eyes away from him. I felt awkward or even a bit scared by his look. It started when I asked him, “How’s she taking it?” In Japanese, “*Okusan-no-okimochi-wa-do-desuka?*” In a more direct translation, it would be something like, “How does she feel about this?” I recall so well that I immediately regretted what I had said. I stammered when I named his wife. Obviously, I must have been nervous when asking him this question. I wished I could take back every word, because it was so obvious that his wife felt terrible about the news. I felt bad because I must have sounded like one of those Japanese TV reporters who ask people this type of question in a sympathetic way, for instance, asking those who just lost everything in the Tsunami disaster in Fukushima in 2011. Why did I ask it then? Before asking him this question, somehow a memory flashed in my mind. After I made the film *Ippo*

*Ippo* in 2010, one of the critiques I received from the committee at the Japanese film festival was:

“As a student work, it is acceptable, but we get the impression that the director is unable to objectively view his footage because somehow his illness (experience) is affecting him negatively... could he not have asked more questions (of his subjects) and sought sharpness (in his approach)?”

I was frustrated by their comments and the way they saw a filmmaker as someone in the same line as doctors, or scientists, with an objective point of view being a crucial skill to making a good film. They argue that one's illness experience is something to overcome and control in order to achieve this. The idea was very different from the one I had learned from *Ippo Ippo*. They often talked about how to patiently live with their illness. My filming approach was patient and friendly, and also respectful in that I was waiting patiently until the critical moment unfolded itself in front of the camera. I did not want to be like a doctor who is impatiently trying to convey his concern about the patients by asking sharp questions, similar to a surgeon using a surgical knife when operating. Again, why did I ask such a surgical-knife-like question of Okamoto-san? Pondering this, I realised I had not used a knife, but I simply acted on empathy. I was concerned about his wife who always greeted me nicely whenever Okamoto-san invited me to come to his house. In this situation, my obvious question certainly seemed to bring our conversation in the direction Okamoto-san had kept quiet for over six years. However, I believe that had I not asked this obvious question, I would have ended up like a surgeon. In this context the obvious question was a way for Okamoto-san to let me in. It became a sentence that was easier to answer, and from there on, as the flow started, we moved on.

Being able to eventually follow Okamoto-san's flow and accept his way of seeing our worlds as separate was perhaps due to three other important encounters I had during my PhD fieldwork and which I will look closer at in the next chapter. Each one of these highlighted to me different ways of relating to the world of shadow. I was able to follow Marsha-san and her husband, who belonged to different worlds; she was a

cancer patient, while he was her loved one, the family member. Not only were their worlds clearly separated in everyday life, they also seemed to find a way to make the world of shadow a bright one so that it cast a light on the world of illness in which the wife was situated. Furthermore, I had the chance of meeting and becoming close with Ishida-san, an elderly woman who also experienced being a family member of a cancer patient and who thus belonged to a different world to mine. Together with her I experienced we could meet on common ground and truly understand the needs of the other so that the borders between our two worlds were minimised. Finally, I found myself in a situation where all the Japanese social codes were broken and lack of sensitivity completely broke off any possibility of letting the two worlds either be opened up for understanding, like with Ishida-san, or to symbiotically work together, like with Marsha-san and her husband. Together, these three encounters taught me a lot about the different possibilities and limitations of communication and understanding between people belonging to different worlds of cancer.

## *5. Chapter Five*

### *Three Encounters in the World of Cancer in Japan*

#### *5.1 Fluid Silence between Husband and Wife – Two Worlds Meet*

I met Marsha-san during my initial fieldwork in Japan in 2009. I was immediately intrigued by her. She was cheerful and it felt good to be around her. At the same time she struggled with many serious health issues, and it fascinated me that she could be so welcoming when meeting others, including me. It was during the preparation for Ippo Ippo's yearly event of climbing Mt. Fuji, which was the first for Marsha-san, that I also met her husband, Shimo-san. She told me that they often went walking together, to train for climbing and because it was good for her osteoporosis. As her eyesight is very poor, they always had to walk arm in arm. Shimo-san would often pick her up after the group meetings, and I got to talk to him now and then. It was during one of these occasions that he told me his passionate hobby was playing tennis. However, Marsha-san never joined him on his weekly visits to the tennis court. This made me very interested in the dynamics of the couple. It was obvious to me that Marsha-san could not play tennis due to her poor health, but I wondered why she had not joined him in what seemed something so important to him. I asked the couple if it would be possible for me to come and film Shimo-san during his training, and asked if Marsha-san would join me. They agreed to this, although they both seemed hesitant. I initially thought it was because they would feel shy meeting each other in front of the camera.

Already from the way Marsha-san approached the tennis court, I noticed that there was a tension between them. Marsha-san was reserved, and Shimo-san seemed unsure as to how to respond to her. I was unaware about what was going on with their



communication because I was busy filming. However, when I had the chance to look closer at this episode by reviewing the video material I had from that day, I was able to understand more about the complex dynamics that took place. I realised that on this day, illness entered the world of health, so to speak. My understanding from my conversations with Marsha-san was that until that day and for the past ten years they had had a silent agreement not to cross the boundaries to each other's worlds, but here she was, in his private sphere. The shadow had stepped into the world of healthy. It made me wonder: what are they communicating through what is not said?

As many studies have concluded, illness is accompanied by different forms of suffering, including emotional and physical pain, which are not easy to speak about or listen to. Many Japanese people prefer to anticipate, articulate and respond to suffering through the use of indirect communication, including silence (Ohnuki-Tierny, 1984; Kakai, 2002). It seemed as though Marsha-san and her husband showed a preference for this communication style.

To be able to capture the dynamics between Marsha-san and Shimo-san, I will take an analytic approach to the sequence from the tennis court, where Marsha-san meets Shimo-san for the first time on his grounds. I was using a big camera with a viewfinder when I filmed this sequence, taken from *Ippo Ippo* (2009), making my focus quite divided between filming and trying to pay attention to what went on. As my recollection of what I myself was doing and thinking is a bit fragmented, I will look at this sequence with a more analytical frame, instead of the autoethnographic one. In addition, I believe it is important to look closer at the phenomenon of silence in the context of Japan. As will be shown here, it is what is *not* said between the couple that gives clues as to what goes on and how they relate to each other's worlds. Thus, before I enter into the video sequence, let me start with a short discussion on silence.

Anthropologists have studied different forms of silence. For instance, there are experiences which are not socially acceptable to speak about, and there are also those that exist beyond the limit of language (Basso, 1970; Collins and Bell, 1998; Huby, 1997; Jackson, 2004). According to Hendry, "[T]he spaces in conversation are also

said to be vital in obtaining a deeper understanding of what is being communicated. Often what is not said is just as important as what is said.” (1995, p. 165). As will be evident in the scenes I present here, anthropologists are faced with a challenge when experience is not verbalised or only partially verbalised.

### 5.1.1 The anthropological obsession with talking

Before entering a theoretical discussion about indirect communication styles, including silence in the context of Japan, I will briefly look at the social and existential limitations and possibilities that exist in communication. For instance, people do not always know what to say, and some things cannot be easily expressed in words. In particular, serious pain, deep sorrow, and traumatic memories create communicative difficulties between the sufferer and the other. According to Scarry (1985), pain is an absolute certainty for the sufferer while the listener may question or doubt this because people do not have an objective, independent access to anyone else’s inner experience. Yet Polanyi (1969) argues that we may still be able to know something about the experience of others through their externalisation of verbal and non-verbal expressions. Also, outward suffering is not merely something that is acknowledged or perceived, because it affects and elicits responses in others through affective and imaginative capacities such as empathy (Hollan, 2008; Throop, 2008).

To approach the experience of others, Katherine Ewing (1990) offers a useful framework. She critiques the anthropological standpoint of seeing the self as a static and fixed entity. From her point of view, selves are fluid through use of language; through language, they constantly shift and contradict from moment to moment. Although the idea is tempting and inspiring, her ethnographic description captures shifts only at a verbal level related to what is “say-able”, and does not incorporate the shifts in the realm of silence. In fact, Merleau-Ponty (1968) encourages us to investigate the mutual relatedness between speech and silence. “[L]anguage realizes, by breaking the silence, what the silence wished and did not obtain. Silence continues

to envelop language; the silence of the absolute language, of the thinking language” (p. 176).

### 5.1.2 Silence and indirect communication in the context of cancer in Japan

Lebra argues that silence is a form of active communication in Japan (Lebra, 1987; 2004). In order to maintain social relationships in Japan, people – and especially the older generation – “prefer an implicit, nonverbal, and intuitive communication style over an explicit, verbal, rational exchange of information” (Kakai, 2002, p. 364). To prevent hurting each other’s feelings, which Lebra calls “fragile as eggshells” (1976, p. 43), Japanese people generally follow norms of politeness and formality related to how to express themselves in speech and attitude. Kagawa-Singer (1993) shows an excellent example of indirect communication style in the context of cancer. She interviewed an elderly Japanese-American husband who behaved ‘as if he did not know’ about his cancer diagnosis, although “by speaking about it in the manner he did, he clearly showed me that he did know” (p. 300). Interestingly, Kagawa-Singer thinks that both the husband and the wife were trying to tell her he knows without verbalising it directly. She explains the husband’s motivation in the following way:

It seems he had concluded that “knowing” would not really change his life, so if his family and doctor did not want him to know, he would comply. In this way, he could maintain his daily routine and make plans for trips as he would have before the surgery. He was able to maintain the illusion of not knowing he had cancer and thus not be an emotional burden on his family because they would not feel obligated to directly offer him emotional support for a potentially fatal diagnosis. He was able to achieve a “smooth” recovery and avoid a culturally awkward family situation, and thereby maintain the cultural objective of harmony in their relationships (1993, p. 300).

On the surface, the husband’s pretence of not knowing can be seen as avoidance, but it can also be seen in the context of an expression of empathy, *omoiyari*, towards his doctor and his wife who do not tell him. In addition, his wife is also being empathetic towards her husband because she acts as if she is unaware that he is pretending not to

know. Kagawa-Singer argues that this is not about a denial of reality, but a demonstration of their way of dealing with a difficult reality. According to Ohi (2011, p. 43), by pretending not to know, *shiranai-furi*, about the characteristics of one's illness, a person with cancer can go on performing his or her role as a patient who would recover from the illness they do not know about, so that he or she can maintain harmony in their relationships. However, this is a burdensome virtue for the person since he or she also needs to keep the difficult emotions that cancer evokes, such as fear, anger, sadness and worry, to themselves. It implies that by remaining silent, the person's belief (for instance, "cancer equals death") can still remain and become fixed. The person would have fewer occasions to become involved in dialogue with others, a dialogue which can potentially shape negative beliefs in a positive direction even if talking itself provokes uncomfortable feelings (for instance, "living with cancer"). Thus, the negative consequences of this creative space produced by a tacit agreement between patient and family need to be considered. For instance, Susan Long writes of a family member who provides comfort for a patient, that "[i]n spite of his own feelings, he should go on acting normally, as if nothing had changed, and do his crying in private" (1982, p. 2104). This implies that a patient's suffering is visible as he receives emotional support from his family, but the sorrow of family members remains unseen to the patient and also to health professionals. In summary then, it shows how silence or not talking presents an ambivalent creative space to nourish the collaborative act of maximising ambiguity, which in turn can nourish hope and a sense of the continuation of life. However, it can also be a source of misery and disappointment if one person's suffering is hidden behind the need to support others.

Hendry (1995) explains the practice of maximising ambiguity between wife and husband as the cultural practice of "wrapping", which has its own ethic and aesthetic. When researchers approach such practices, they need to be extra careful about their eagerness to seek accuracy by unwrapping the consciously underlying emotions in people. Hendry argues "the problem may lie in our Western propensity to want always to be unwrapping, deconstructing, seeing the objects at the centre of things." Hendry reminds us, "what we need to do, is to learn to value the wrapping, as well as the wrapped, and seek the meaning they together convey" (ibid, p. 109). In this sense,

Kagawa-Singer seems to understand such value as she shows sensitivity towards the couple by not verbally confronting them with questions which would elicit emotional reactions. This could not only ruin their wrapping – their difficult efforts not to talk – but also what they have wrapped – the maximised ambiguity concerning the scary possibilities of the future as a means of caring for each other. Kagawa-Singer shows that the couple are not merely passively avoiding it, but creatively producing a sense of well-being and self-integrity in their current life situation (1993, p. 295). However, Kagawa-Singer's ethnography lacks a description of the role of the body in their communication, and how she comes to understand these cues from the couple. In the following I hope to enrich the ethnographic understanding of indirect communication styles to help us approach what people are communicating. Caution is needed not to overlook the role of silence in communication because researchers who pay great attention to verbal communication have a tendency to treat silence as a pause, or gap, or as a means for someone to take their turn in conversation (Sacks, 1974). Again, this approach overlooks people's intentions, considerations, and the efforts that lie behind silence in relation to those with whom they communicate. Crapanzano (2004) argues that silence in Japanese compared to the US is not merely the absence of speech, such as a gap, pause, or empty space that needs to be "filled". So, during the encounter at the tennis court, what is the role of silence between Marsha-san and Shimo-san as their two worlds of cancer meet?

To help understand the context of the tennis court scene, I will again use microanalysis as a method. I will also bring in follow-up interviews from the PhD fieldwork with Marsha-san, as well as members from Furatto who watched the sequence during a feedback screening, and who all commented on how they understood the scene. Moreover, I will compare and contrast the behaviour of Marsha-san and Shimo-san with other situations in which they were filmed in order to understand silence as a mode of being that constantly shifts within the self, and between selves in ongoing interactions. By the end of the analysis, I will highlight how a reinterpretation of the scene can provide an alternative, yet empirically grounded, way of explaining the attitude of Shimo-san towards his wife – from what to me at first seemed cold and distant, to more empathetic and caring.

### 5.1.3 The tension between wife and husband

The following link gives access to the opening scene of the film (in this chapter all links are to excerpts taken from the film *Ippo Ippo*, 2010 by Shotaro Wake). The scene starts when Marsha-san visits her husband, Shimo-san, for the first time at the tennis court where he plays tennis with his friends almost every weekend.

Click here to watch the video: [\*Opening Scene of the film Ippo Ippo\*](#)

In the opening scene both Marsha-san and her husband seem to find each other strange and distant. This starts before they meet, when Marsha-san finds her husband is not there to greet her at the gate, and her expectations are let down. Her visit was a special occasion. It was the first time in ten years she dared to come and see his passion for tennis in action, but in the end it did not turn out to be a good experience, and they hurried home.

On the surface, the subtle tension seems typical of a middle-aged married couple maintaining the balance of their relationship after they have raised their children. A wife intrudes on her husband's personal space in public and her husband reacts to this by offering an unfriendly attitude. In fact, at the benches Marsha-san passionately engages in a conversation with other women about the ideal of keeping one's hobbies and interests separate between husband and wife. Given that their children are now grown up, this is particularly important since it allows them both to nourish social relationships apart from each other so they can feel free to enjoy moments with their own circle of friends (*Ippo Ippo* 2010, 00:06:02 - 00:06:43). However, it will become evident that keeping their interests separate has an extra importance in terms of their life together while dealing with chronic disability and illness.

On the way to the tennis court, Marsha-san told me that it was difficult for her to understand why her husband kept playing tennis, especially during the time she had

to go through chemotherapy for her breast cancer. “He played tennis before I became ill. But, even when I became sick, he did not stop. I thought why does he go at such a time, I thought he could pat my back [to comfort me], but now I think this would not have helped me that much. Why did I think in that way? I must have been frustrated.” She then kept quiet for a long time, but I felt her latent anger and sadness from the way she had spoken to me. That Shimo-san left to play tennis in the midst of her treatment seemed to create a sense of distrust in Marsha-san, and it has become a painful memory.

However, what Marsha-san did not seem to grasp at the time of our visit was what it meant for Shimo-san to keep playing tennis, particularly when his wife was going through cancer treatment. Shimo-san once told me that it was exactly because of this difficult time that he needed to continue playing tennis. For two decades he had been supportive of his wife – first with her partial blindness, and later with her cancer treatment. Moreover, during her treatment he had to deal with other stressful family issues, such as the health problems of his grandmother, his son’s high school entrance exam, and two hours of commuting to work every day. It was a heavy burden to survive the pressures and responsibilities of a householder, a father, a son, a husband, and a caregiver. Moreover, his wife’s serious illness evoked his own existential issues, such as those of realising his own health might also be temporary. He could no longer take his health for granted. I understand why Shimo-san told me this in a shameful, somewhat defensive way. He knew that his need for this hobby contradicted the expected image of a “good caregiver” in the world of illness. According to Susan Long, good caregivers in the Japanese sense are those who protect, endure, and sacrifice themselves for the wellbeing of the ill family member (2004).

In this view, Shimo-san’s tennis playing does not appear to follow this norm of a good caregiver in the midst of his wife having a hard time. However, by talking to Shimo-san I realised that playing tennis made him feel refreshed, and provided a sense of wellbeing so that he could continue to be a good caregiver. In Gay Becker’s terms, playing tennis was his way of “restoring the sense of normality and continuity in middle of the chaotic life situation” (1997). What the couple did not seem to talk about

openly was the burden felt by Shimo-san as a caregiver. I imagine this is not unique for those in a similar situation in Japan. In the case of Marsha-san and her husband, the non-verbalised issue manifested in silence becomes vividly elicited through the awkward encounter when she sees him in a different situation, among people she does not know, in a world she has little access to and understanding of. Radley discusses how a person with a chronic condition, as is the case with many types of cancer and handicaps, still has to live in the world of the healthy where they feel they do not belong (1993; 2009). If I think of the world of the healthy, a tennis court represents one of the most vividly healthy places. For Marsha-san, who cannot even see the movement of the ball, this healthy place could even be a dangerous place.

In the following I will closely examine how they negotiate their boundary of privacy and autonomy, not simply as wife and husband, but also as long-term care-receiver and caregiver, in a place where they find each other strange and distant. By closely examining how their subtle conflict emerges, and how they make an effort to recover from it, I find that I am forced to pay attention to their bodily communication, particularly during periods of silence.

#### 5.1.4 Silence and the verbal expression of “hot”

In the opening scene, viewers hear the word *atsui* (hot in English) eight times. Marsha-san mutters it to herself three times and the other uses are between her and her husband in conversation. The semantic meaning tells us she is expressing something about her physical state; she feels warm beneath the strong sunlight on a summer’s day. However, I argue that only following the semantic meaning of her expression will provide limited clues as to her full experience. After exploring the pragmatic meaning in her expression of “hot” in relation to what takes place in and around her silence, the viewers understand how its meaning shifts each time according to her state and interactions with others. To clarify the depth of the pragmatic meanings I start from the moment she says “hot” for the second time while standing in the middle of the field.





Figure 26: How to approach her husband at the tennis court<sup>8</sup>?

At that moment I was filming her from some distance from behind, and I could hear her muttering the word because of the microphone attached to her. Because she was looking away and we had a physical distance between us, I thought she was talking to herself when she said “hot”. However, from micro observations, I came to realise the complexity around the expression which I heard during editing. For instance, with a tiny voice she mutters “*Mai...*” and “*Doko...*” right before she says “hot” (*Ippo Ippo* 2010, 00:02:04 - 00:02:13). These mutterings have not been subtitled because, again, I only heard them during the editing process. In the following link “*Mai*” and “*Doko*” are embedded in the subtitles.

Click here to watch the video: ["Mai" and "Doko"](#)

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<sup>8</sup> All pictures in this chapter are screenshots from the film *Ippo Ippo* (Wake, 2010), filmed in 2009.

The problem is that even after I recognised their presence they were still only fragments, half words or half sentences. Their significance was unclear and some imagination is required to grasp their full meaning. If I were to guess, “*Mai...*” stands for “*Maitsutana*” (what should I do?) and “*Doko...*” stands for “*Dokokana*” (where...?). They seem to indicate that she does not know where or how to find her husband. This interpretation is in line with what she has already said: “If he doesn't see me. I can't approach them.” Her body also seems to correlate with the meaning of the fragments of words; for instance, she says “*Mai*” and looks around uncomfortably to the left and right, and says “*Doko...*” while she lifts up her left leg, as if trying to make a move, but she does not. Instead, she stands still and says, “hot” as if she is nailed to the ground. This leads me to a deeper understanding of her inner state. She seems to say, “hot” because she is hesitant in showing me that her husband is not coming to pick her up, but she does not know how to approach him without my help. Interestingly, feeling hot beneath the burning sun may be the only certainty she experiences in an uncertain situation and in an unfamiliar place.

I remember seeing her standing alone in front of my camera, amplifying intensely my feelings of awkwardness and guilt, which made me more aware about my carelessness in prioritising my interest in filming over accompanying her as a guide because of her poor eyesight. As is evident in Huby's work on silence (1997), silence calls for interpretation and action, and her silence communicated to me in a way that elicited guilt for not behaving appropriately. It was as if I was waiting for her to make the next move and I felt increasingly affected by her silence. Indeed, it was me who could not take her silence any longer, so I made the next move. I stopped filming, approached her and accompanied her to the people at the bench to, in Montagu and Matson's term, “make an entrance” (1979, 2) for the encounter. Marsha-san accepts my initiative without speaking and starts to walk towards the bench.



*Figure 27: Wake's filming position and angle.*

As shown in the Figure 27, I stand slightly behind and to the left of Marsha-san and start my camera again just before she greets them vocally. This suggests that what is visually missing between the shots is the short period in which I shift my role from cameraman to a seeing assistant. In this period when the camera is off and visual material is missing, I appear to set the stage for an encounter between Marsha-san and the people at the bench.

This microanalysis shows that her utterance of “hot” becomes an index of (and illuminates the boundary between) knowing and not knowing, of being able and unable, hopeful and hopeless. Importantly, my reaction underlines that her experience is not an isolated, disconnected personal entity, but a shared one. The silence ran fluidly between us, communicating. Using this logic, silence is also a dynamic phenomenon where ongoing interactions constantly shape meaning. In the next section, I will look more closely at how fluid silence is shaped between Marsha-san and her husband at the tennis court.

### 5.1.5 "Hot" as an Expression of Reclaiming Each Other in an Unfamiliar Situation



*Figure 28: Expressions of "hot" between Marsha-san and her husband.*

Their first encounter at the tennis court suggests that both Marsha-san and Shimo-san do not know how to treat each other in this unfamiliar situation. Yet they work hard without saying much to reconcile their relationship and reduce the feelings of awkwardness. For instance, Shimo-san lets her (and me) sit on the bench next to where he plays, and brings her a cap to wear. Also, after the game Shimo-san offers her a cold drink (Figure 28), and says, "It's hot, isn't it?" and Marsha-san replies quickly, "So hot". Her utterance of "hot" sounds more like an expression of concern and care, which is different from when she was standing still and alone. Again, feeling very hot under the burning sun is a shared experience they can easily agree on, and therefore a safe topic in this public environment.

In the next shot, they are resting quietly in the shade. Here Marsha-san is standing while her husband sits on the bench. It shows who needs care in this situation, and the attention is given to her husband who is physically tired from playing the game. Basso reminds us to pay attention to who breaks the silence, as well as when and how, because it reveals "the nature of [a person's] relationships to other people" (1970, p.

216). In the Apache Indian context, parents and children refrain from talking for a long time after having lived separately because the children attend school in the city. Most often it is the children who break the silence. In this way the parents can observe if the children are still the same, and, let's say for instance, do not act disrespectfully towards them. Thus, what began as a feeling of difficult talking is shaped into one of easy to talk with their children. This feeling of easy to talk is related to familiarity and predictability in the behaviours of others (ibid, pp. 221-222). In the scene, Shimo-san is the one who breaks the silence by saying, "It's really hot today" and Marsha-san nods. For Shimo-san, being with Marsha-san in silence does not seem to cultivate an easy to talk feeling, familiarity or predictability. The utterance is a search for a topic of conversation to try to reduce the awkwardness between them. However, interestingly, Marsha-san's response, "Are you going to play again?" seems an uncomfortable one for Shimo-san, who lowers his voice and gives a blunt answer, "Unless you don't want me to." He almost takes offence, as though she has already had enough of watching him play after viewing only one match, rather than interpreting it as her concern for her husband's physical condition in the extremely hot weather. Shimo-san goes on and plays more games despite Marsha-san's warning ("You'll wear yourself out"). After the game he hurries back to her and quickly starts packing his tennis bag to leave the field. He is not in the mood to share news about his game with her, and his behaviour seems to make Marsha-san frustrated. His frustration seems to be in line with the guilt he felt when leaving his wife hanging around while he is playing tennis. Feeling guilt for not taking good care of his visiting wife means playing tennis is not as much fun or as refreshing as it usually is for him. Marsha-san reacts to his comment and says, "What do you mean "left to hang around"?" She goes on to say that she would not have visited him at all if Wake (the researcher) had not asked her, and she would not return again. At this moment, despite the awareness that they are being filmed, they could not keep cool and start verbalising their frustration. Shimo-san turns away and continues packing his bag rather than answering Marsha-san. This is his way of avoiding further verbal conflict, which they may think is embarrassing in public, especially on camera. In this sense, much of their frustration remains without being verbalised but still affects the mood of both.

### 5.1.6 Corporeal resonance or dissonance in silence

The tension between Shimo-san and Marsha-san continues until they go home. On the way back home, by the stairs, Marsha-san asks him to wait for her, and he offers her a hand. He says, “hot”, as soon as they hold hands and Marsha-san echoes the same word. They seem very shy about holding hands in front of the camera, signifying a closeness and intimacy despite feeling uneasy about each other in the moment. They then go up the stairs without talking. The way they walk together seems to express their feeling of uneasiness and awkwardness towards each other. For instance, they try to synchronise each other's footsteps physically yet do not quite make it and they let go of each other's hands as soon as they make it to the top. Although they do not say anything, their bodies tell a story.



Figure 29: On the stairs on the way back home.

Click here to watch the video: [On the stairs on the way back home](#)

In order to highlight their corporeal dissonance in this scene, let me contrast it with another scene when they walk together in a good mood, in a place where their health status does not matter, and where they are in the same world.





Figure 30: Walking together near their home.

Click here to watch the video: [Walking together near their home](#)

In these sequences, their walking pace and the rhythm of their motions are beautifully synchronised. Marsha-san seems comfortable in matching her husband's walking speed and does not worry about the possibility of stumbling on a stone or anything else. Her body shows that she trusts her husband in this situation. The resonance emerges not only from their physical movements but also through their positive mood and the content of their speech. Also on this walk they have to walk up some steps and here too, as in the scene from the tennis court, their footsteps do not match (her husband is one step ahead); however, the difference is that they quickly re-match their footsteps after reaching the top, so that they can again regain a synchronised walk. This can be contrasted with the stairs at the tennis court where they quickly released each other's hands at the top. The difference in walking rhythm points to the fact that the couple could not recover their sense of familiarity and closeness on the day Marsha-san visited the tennis court, and it highlights that the boundary between illness and health usually remains hidden in their everyday life. Yet, the following episode suggests that her visit certainly provided Marsha-san with a new understanding of how to treat the boundary between the two.

### 5.1.7 New understandings of the boundary between the couple

Four years later I had the opportunity to catch up with Marsha-san at the cancer support group during my most recent fieldwork. She told me that she never went back to visit her husband at the tennis court. Yet, interestingly there seemed to be a positive change in her behaviour towards her husband's tennis playing as a result of seeing his world, "another world" (*Ippo Ippo* 2010, 00:07:00 - 00:07:13). For instance, she now sometimes prepares rice balls (*onigiri*) for him when he goes out for tennis, which is something she never did before. It is a handmade lunch, *tezukuri-bento*, and a symbol of intimacy and support; although Marsha-san is not physically present, her handmade gift is carried into and appreciated in Shimo-san's "world". Marsha-san seems to understand now that her "world" is the cancer support group where she can feel free from her role as a housewife and enjoy quality time with other cancer friends and supporters. She said jokingly that if her husband had been present at the support group meeting today, "I would have acted differently" and that would have spoiled her fun. Other women also laughed to show that they could not agree more. This is most probably what she later understood was happening to Shimo-san when she visited him in his private sphere, creating awkwardness. Shimo-san's tennis belongs to the world of the healthy and Marsha-san's cancer group belongs to the world of illness. A degree of acceptance in Marsha-san of their differentiated positions due to her chronic condition and his caregiver duty has been nourished.

I also discovered that their decision to keep their interests and social relationships separate is not merely due to self-interest (to experience more fun and feel freer). There is also another important dimension that I initially did not understand. This became clear to me in my most recent research only after I started to socialise and engage with families affected by cancer, i.e. those who have experienced a role similar to Shimo-san's. Based on feedback I received during film screenings to a non-Japanese, mostly Scandinavian audience, I notice that some tend to see Shimo-san as a cold and distant husband and supporter. However, when I showed the sequence to



members of Furatto, they spoke highly about Shimo-san's attitude as a caregiver, especially his decision *not* to come with Marsha-san to Mt. Fuji. They see it as a non-selfish choice and do not interpret it as a lie. Instead they see it as a clever and generous consideration towards Marsha-san.



Figure 31: Discussing the support of Shimo-san.

Click here to watch the video: [Discussing the support of Shimo-san](#)

If the norm of good caregiving is related to a sense of participation, as suggested by Long (1982; 2004), then the way Ishida-san, Takeuchi-san and Okamoto-san discuss how the husband's choice of not joining the climbing as a benefit to Marsha-san and thus as good support, is contradictory. Their rationale is based on the fact that due to his absence, other supporters would feel more obliged to help Marsha-san and to consider her security; otherwise, they would feel hesitant about offering her a hand in front of her husband, and Marsha-san would also feel less able to openly seek help from male supporters who are more experienced mountain climbers. They could also empathise with how difficult it must have been for Shimo-san to wait for her to come back home safely while bearing his difficult feelings. In this sense, I assume that when they were walking in a good mood and Marsha-san asked her husband to join the climb the following year, his response of "Okay, I will" could on a superficial level

be treated simply as a promise that he does not intend to keep. This would be seen as a cold, *tsumetai*, response. However, according to the interpretation of the members of Furatto, the meaning of his response is more like, “I would like to go with you although I think I had better not.” Shimo-san is pretending he will go, *iku-furi*, with Marsha-san, which is an expression of empathetic consideration of Marsha-san’s condition. This sentence may still be seen as a bit cold to the Western audience. However, it could be translated as, “I will be here for you so that you will be able to manage the challenge by yourself”.



Figure 32: Marsha-san’s husband pretends he will go to Mt. Fuji with her.

Click here to watch the video: [Walking together near their home](#)

The video shows that it is not easy for him to find the best way to answer her question, which is evident from his body language as he looks down at the ground slightly before he replies, as if he is thinking of how best to respond to her. Therefore, his response could be seen as an expression of his warm, *atataakai*, feelings towards Marsha-san. If I follow this logic further I start to think that perhaps Marsha-san’s invitation is also a kind of test, as though she invites him, *sasou-furi*, but it does not really matter whether he joins or not. Rather, she wanted to see how he would respond

to her invitation. More simply, through talking about the trip to Mt. Fuji, they seem to genuinely assess their feelings towards each other.

In such a moment of intimacy their physical, emotional, and verbalised actions all point in a certain direction, and their synchronised movements make it difficult to observe the boundary of health and illness between the two. Shimo-san's response is one example of producing the possibility of something joyful for the future, and that is highly precious and welcome to those who suffer from illness and disability, as frightening and worrying possibilities are more common to them. Although such possibilities carry the risk of unexpectedly becoming a source of conflict because of the potential need to renegotiate boundaries (as we saw with the tennis - Marsha-san and Shimo-san must both have had a positive expectation before she arrived), I still believe they have enough experience and skill to cultivate good teamwork to manage that risk creatively, as when they walk arm in arm, step by step, *Ippo Ippo*, during this tough journey. Ultimately, I believe that their long marriage is still *atsui*, hot, although I am certain that Marsha-san and Shimo-san would not publically agree on this.

It seems, then, that expressions of silence, including short phrases like "hot" are closely related to the emotionally sensitive topic of Marsha-san's cancer diagnosis which they have never talked about, but kept wrapped. The encounter at the tennis court underlines the boundary that exists between the couple, not only as wife and husband, but also as sufferer and caregiver. The analysis follows the process of how they negotiate the boundary in worlds where they find each other strange and distant, and how they try to avoid an open verbal conflict while at the same time also trying to rebuild a sense of familiarity and predictability. Although the encounter comes out as a rather tough experience during the visit itself, four years later it certainly seems like the encounter has brought a new and positive change in the behaviour of Marsha-san, who seems to have started to appreciate and respect her husband's boundaries. As has been shown, the meaning of the utterance "hot" differs from moment to moment, very dependent on the silence used, and it seems reasonable to argue that silence as a mode of being is constantly shifting in relation to utterance, body, relationship and circumstances. Through their delicate manner of approaching each

other, they have found their way of living side by side in a *heiso* relationship, respecting each other's worlds and the borders between them, still listening to what the other says in the silence.

In the next encounter, I describe a situation where the listeners, nursing students, show a strong interest in understanding my cancer experience. However, I did not feel understood, and I will discuss why in the next section.

## *5.2 Trying to catch my Kokoro. An Encounter with Nursing Students*

While I was searching for somewhere to conduct my PhD fieldwork in Japan, I visited a local event called Relay for Life (RFL) to greet those I met during my previous research in 2009. RFL is a cancer charity event which originated in the US, but which is becoming more and more popular in Japan. In 2012, RFL was held in 30 places across Japan, and to my knowledge they raised over £300,000. In RFL people who are experiencing or have experienced cancer, and those affected by cancer (family, friends, etc.) are called cancer survivors. Cancer survivors and their supporters walk lap after lap throughout the night on a track and field stadium. The aim is to raise funds for ongoing cancer research and education, and to develop new treatments. The aim is also to raise social awareness against the prejudice about cancer that people are met with, and to ask for better social understanding and support. In accordance with the ideology of RFL, any topic related to cancer can be shared during the event. Survivors are encouraged to talk about their experiences and supporters are encouraged to listen, so that a new understanding can be creatively produced.

While I was walking on the track and reigniting my old relationships with people I knew from before, Takao-san approached me. She is a middle-aged mother and cancer survivor, and one of the organisers of the local RFL. She had already been informed that I would be there. After we greeted one another, Takao-san said to me kindly: “There are some students from a nursing school here who are very eager to hear Wake-chan’s story.” I saw some female students in their early 20s looking at us from a booth next to the track. I tried to smile, hiding my discomfort. I said “Really? But I am fine.” I could not see myself sitting in the middle of a group of young female students, talking about my painful story, even if they were soon going to be health professionals. I tried to talk myself out of it while remaining friendly and polite, but she was holding onto my arm and would not let me. It made me realise it would be difficult to get out of the situation without her losing face. I felt obligated not to let this happen. I saw that she was both trying to be nice and to create new connections between survivors

and young nursing students. Perhaps she thought I would be an interesting guest on this occasion since I was the only the survivor who lived abroad. When the students saw that I no longer tried to walk away, they started to clap their hands happily as though I had said yes. Their friendly manner made it difficult for me to say no. In addition, if I went on rejecting the invitation, I too might look bad. In the end I promised Takao-san to come back later, but I asked if it would be okay for me to come back with other survivors. However, it proved to be difficult for me to find others to come with me. I asked Nabe-san who is usually open about her cancer, but when I told her it was nursing students who wanted to hear our stories, she frowned and said, “But they wanted to hear Wake-chan’s story, right?”.

She was indirectly saying no. In the end I found three other survivors who agreed to join me who were already skilled in talking about their cancer experiences in public.

There were about 15 female and a few male students sitting under a tent in a booth. The sun was setting, but I could still see their faces. Takao-san was happy and asked the students to offer us some chairs, a welcoming gesture, *omotenashi* in Japanese, showing politeness and respect. With effort, the students managed to put the chairs in a circle. I understood they were trying to include everyone as a group in the discussion. However, as their bodies and eyes were concentrated on us, I still sensed an emotional distance between us. Their focus made it difficult for me to appreciate their politeness and eagerness to listen to our stories. Some of them might also have been intimidated by my appearance, due to my height, long hair and a three-to-five-day old beard.

To get the group discussion started, Takao-san asked us to introduce ourselves. She first asked survivors to share their names and type of cancer. Two survivors voluntarily added some medical details to give a clearer picture of their current condition. An elderly man sitting beside me told the students that he did not have cancer himself, but that he had lost his daughter to cancer nine years ago. When my turn came I told them my last name and type of cancer, and as I preferred not to share my medical history and condition I quickly tried to move on to another topic. I started talking about my academic occupation and my research objectives, such as being a PhD student from the University of Manchester coming back to conduct further

research into the lives of people living with cancer, and those close to them. I made sure they understood what I meant by “coming back”, as people often confuse my ethnicity from the way I look, especially when combined with my foreign student occupation. I told them my mother was from Switzerland and that I was born and raised in Japan. I was used to introducing myself like this since I was a little boy. It has not only been a way to explain who and what I am, but usually evokes people’s curiosity and leads to further conversations. However, from their responses I immediately understood they did not care about anything but my illness identity. There were no comments or signs of interest, only puzzled faces. To try to see things from their point of view, they may have felt a bit lost because they got too little information related to my illness history and medical condition, but too much unrelated information, and they might have felt it impolite to ask me more. In return, Takao-san asked the students to introduce themselves, what year they were in with their studies, and their desired workplace after graduation, if they had already decided. They seemed happy and animated when they provided the information, especially when talking about the hospital or institution which they were a part of, and they seemed to put emphasis on the future awaiting them. The introduction set our positions and expectations straight within the group setting: while survivors were asked and expected to give information related to their traumatic past in the sphere of illness and suffering, students gave information related to their bright future in the sphere of health and care.

After the introduction, Takao-san encouraged the students to go on asking us questions. She said, “This is a rare opportunity for you.” The students looked shy and hesitant, looking at each other or simply facing down. I felt quite awkward, as did the other survivors, since nobody seemed to want to ask us any questions. After some time, one energetic female student took the lead and asked us cheerfully – or I may have misinterpreted it as cheerfully – “Could you please tell us about your feelings when you heard your diagnosis?” I immediately thought she was too direct and tried to step into our hearts (*kokoro* in Japanese) too quickly by asking a very personal question about our feelings at a moment of existential crisis. For instance, I would be especially careful when asking an older male such a question since it might be

considered impolite and disrespectful, as if I had tried to look into his *kokoro*. Rather, I would start by warming up our relationship, and then eventually ask about his *kokoro*, but in a softer way and more indirectly. Furthermore, I would not ask about his emotions because I already know the answer: they are painful and hard, and what more can he say? Why was the nurse student breaking this rule, especially with such a sensitive topic? Something had gone wrong with the communication rules, and although she may have wanted to learn something, the loss of sensitivity made this difficult. What she achieved, however, was to make me angry and the others uncomfortable.

As I struggled more and more to suppress my anger underneath a smile, I honestly have to say I do not remember how the other survivors reacted. I do recall how their faces tightened up, how the tone of their voices became slightly darker, and how they tried to talk about issues related to practical matters, such as what their doctors had said to them about treatment and their prospects, and describing their physical condition rather than talk about the feelings they had. As my turn approached, I suddenly heard someone familiar calling my name. I saw Mishima-san with a big smile on her face as she waved her hand at me: “Wake-chaaan! It’s been a while, hasn’t it?” Inside me I said “Saved!” and left my seat without looking back. I knew it would seem rude to leave in the middle of the conversation, but I also knew I could be excused because I was greeting somebody whom I had not seen for a while. I explained the situation to Mishima-san and thanked her for showing up; it was perfect timing. She was sympathetic and said “Who you talk to and how and when you like to do so is your decision!” I felt good that she immediately understood my feelings. Mishima-san used to be a member of a cancer support group where I participated as a member during my previous research. While we were walking on the track, she said angrily “Why do we even have to walk because we got sick?” I could not agree more.

Following the event, I met with Takao-san on a number of occasions. We always greet each other as before, and I wanted to know if she was offended by my act of escaping from the group conversation, but neither of us ever brought it up. At least on my part it was to avoid any discomfort from the situation.



Looking back, I find it interesting that I did not let the students hear my story in the way Stoller was open with me. If he had shown me the wisdom of being open to people, why could I not do the same? They have the same position as I had – they wanted to hear and understand about experiences related to illness, including the suffering and pain that has a strong impact on all survivors.

First of all, I believe that from the start, they did not produce a connection and trust, but did the opposite of what would make me and the others feel comfortable in the situation. For instance, the invitation was somehow forced, the students did not voluntarily line up the chairs to include us as part of the group, and the introduction only highlighted our differences and served to further divide the role between speaker and listener. Moreover, none of the students took the initiative to ask questions. When a question was finally asked, it seemed to me they were being insensitive and impolite asking such a personal question related to the emotions of someone older than them. I simply felt awkward sitting on a chair and being expected to talk about a topic they wanted to hear about, but not about the things I would have liked to talk about, such as my student life in UK where I was researching the very same topic.

The mismatch I felt with the students seemed to be the result of a cultural clash. For instance, RFL is based on the American cultural model with the ideology of openness and being positive. In this sense, the ideology of RFL can be said to be like a cancer school where cancer participants learn and practice opening up their *kokoro* by talking and being visible in public space, so that they can be politicised and publicised, and thus challenging the stigma around cancer. However, in Japan and many other cultures, illness in general belongs to the private. Thus, mixing the private and public creates an uncomfortable feeling for many. Returning to the situation with the nurses, if it had been a normal situation, my age and educational status certainly would have influenced how we communicated, and it would probably have been natural for me to take the lead in the conversation. However, the only thing they seemed to care about, which I did not see, was my status as a patient. They wanted to take on a role as listener as part of their professional training. Yet, they still acted as youngsters, as

though somebody had to take the initiative for them in order for them to take on this role. In this setting, my age and educational status had been discredited in an embarrassing way.

This episode highlights the difficulty of finding a balance in the communication between patients and health professionals. It is not an easy task, as many elements contribute to the challenges. It emerges from the sharp difference in status and roles between the two groups, as well as the different experiences the two groups bring with them. Although the nursing students were still amateurs, they were already representatives of the medical world. They were educated and trained to understand patients as patients. It was simply the wrong context for me to try to be friends with them since they were not interested in my academic status, but made me feel like I was an object to them, much in the same way as I felt in the US. They simply wanted me to act as a patient, however unique I might be, so that they could learn from my real life experience as a cancer survivor, thus providing them with crucial knowledge they could bring with them to their medical practices after finishing school. We both probably left with a feeling of not being understood and that our worlds are separate. This, however, is in contrast to how I felt after one of my first meetings with Ishida-san.

## 5.3 Sharing the worlds of cancer

I will never forget the day I got to know Ishida-san. She is in her late sixties with a good taste for fashion, her golden-orange coloured scarf and nicely set silver permed hair highlighted her smile. I met Ishida-san as a roleplay partner in a communication skills training workshop during a seminar for “Cancer Peer Supporters”<sup>9</sup> (“*Gan Pea Sapoutasu*”, in Japanese). The seminar was for those who were interested in becoming peer supporters, defined by the programme as “those who share experience, and think together, and who are expected to provide emotional care for their peers, thus those who have similar cancer experiences”. As I mentioned earlier (see Section 1.1), the “Cancer Peer Supporter” project is operated under the commission of the Ministry of Health, Labour and Welfare in Japan (Japanese Cancer Society, in the Cancer Peer Support textbook, 2013, p. 11), and was developed by leading oncologists as well as leaders of NPOs (non-profit organisations) related to cancer.

My understanding of why people affected by cancer are now being recruited as caregivers is that there are too few care providers to meet the needs of the increasing number of cancer patients. Ongoing cuts in cancer provision in Japan are part of the overall decline in the universal health care system (Fujiwara et al., 2015), while demands for emotional and psychological care are increasing, not only by patients, but by those who are afflicted by it, such as families and the bereaved. The field of medicine seems to see this last group as a potential resource that may help reduce the burden on the increasingly stretched medical field. It looks to me that this programme forms a part of cancer schools where they teach the basics of emotional care to non-professionals so that they become a resource to the medical field. It appears that organisers rely on the valuable resource that those interested in becoming peer supporters have, but doctors do not: time. According to the programme textbook, the basic function of peer supporters is to “listen carefully” and that is a “special task”, which differs from other health, social welfare, and administrative professionals,

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<sup>9</sup> All translations from the Peer Support Textbook are done by Shotaro Wake.

because they are expected to be emotionally capable enough to understand and help reduce alienation and provide relief for their peers:

Some peers would prefer if their friends and acquaintances did not know about their disease. They may be able to ask health experts if they have specific questions, but it is difficult to find someone who is willing to ‘just listen’ to their worries” (Japanese Cancer Society, in the Cancer peer support textbook, 2013, pp. 18- 23).

Thus, the programme focuses on teaching peer supporters how to listen according to the ways in which they define proper listening. It seems to me that Japanese policymakers are trying to insist upon the standard communication style by offering an educational programme for people afflicted by cancer who are interested in becoming “cancer peer supporters”. I thought that by joining the seminar I could learn something about what is considered good listening as an expression of emotional support in cancer support communities in Japan today. Also, I became curious about whether they were teaching something that would be useful in helping me better understand things that are difficult to talk about and suffering that is not visible for others.

The highlight of the seminar was doing role-plays in small groups. The participants seemed more joyful during these sessions than when they were sitting quietly, listening to the lectures. The aim of the role-play workshop was to let the participants practice their facilitating skills as peer supporters and to become more familiar with handling any type of concerns and problems that cancer patients may come to seek their advice about. I was not familiar with role-playing, and later learnt that the method is widely used as a participatory way of learning in the fields of academia, business, and medicine because it is seen as realistic, compared to standard, lecture-type scenarios (Eagles et al., 2001; Rees, Sheard and McPherson, 2004). At the time, I knew little about the various emotions and to what degree emotions could be elicited.

I was assigned to be on the team with Ishida-san and another elderly man during the role-play. I was a little nervous about whether I could do the role-play well, but their

friendly, polite, and modest attitudes towards each other and me made me feel comfortable in the team. Ishida-san has a nice smile and when she laughs, which she often does, a sense of wellbeing, joyfulness, and health is revealed (see Figure 33). At the time, I knew Ishida-san briefly as a volunteer at the O Hospital where the role-play took place. I did not know anything yet about her rich experience in socialising with patients and the medical staff at the O Hospital through the garden in the patio of the hospital she tended. She spends most of her day at the hospital, and it was where she spent the final days of her husband's life.



*Figure 33: Ishida-san in the garden of the O hospital, 2013. Photo by Shotaro Wake.*

To start the role-play sessions, the instructor divided the 20 participants into groups of three. One person in the group took on the role of the cancer patient, or his or her family member, another person took the role of the peer supporter, and the last one that of the observer.

In the first round, Ishida-san was given the role of the listener, and I was given the role of the patient. The instructor gave me a handout that described the character I was to perform. My character was a 72-year-old male, who was married and had children. I learnt that “he easily gets tired when he does his hobbies of going for a hike and drawing pictures. He keeps talking about how his recovery is too slow and not going

as well as he had hoped. He believes that it is due to being hospitalised too long as well as his doctor's poor surgical skills." I was not quite sure how to do my role and my confidence as an actor was not very high, but I wanted to give it my best shot. Ishida-san and I moved our chairs and sat like the scene in the video that had been shown to us about proper listening: we put our hands on our knees, sat up straight, and faced each other, not directly, but slightly outward in such a way that our knees met without us sitting opposite in a straight line. The instructor announced the start of our sessions:

Wake:           Excuse me.

Ishida-san:    Yes.

Wake:           Is this the right place for me to seek advice? I found out about my colon cancer six months ago. I had an operation and felt better three months later. But I do not have any appetite. I am low on energy and get tired very easily... I go for a walk sometimes, but not like I could do before... I feel like neither my wife nor my children understand me. It was all because I was hospitalised for too long, and my doctor did not do a good job... that doctor... if my doctor had done it right, I wouldn't have been in this condition. I can't forgive him.

Ishida-san:    I too had an odd doctor at the orthopaedic department during the time of my husband's treatment. Even though we have our doctor-in-charge, if the department is different...

Wake:           The doctor did not listen to me at all! He only did a little... then it was soon finished. It's his fault that I ended up like this.

Ishida-san:    Did you not experience anything nice during the hospitalisation? You did not find other patients whom you could talk to?

Wake:           I don't know about the other patients! I feel unfortunate to have met such a doctor. The doctor did not listen to me at all. He listened briefly, but that was it. Everything is my doctor's fault. It is my doctor's fault that I ended up becoming like this.

- Ishida-san: Anything good, no? With other patients?
- Wake: They tell me about their surgery. I found it different from my case. I'd like to hear what other patients think about this doctor. I don't know if it is ok to visit them one by one?
- Ishida-san: If you are dissatisfied with the hospital, unfortunately I cannot do anything about this. However, there are social workers at the hospital whom you can meet. I understand that you may not be satisfied with this, but it might move things forward... We peer supporters handle worries more related to everyday life, so for the things concerning you I would recommend you go to the consultation desk at the hospital.
- Wake: Would you show me where I could meet them, exactly?
- Ishida-san: We have an office.
- Wake: Really? In this hospital?
- Ishida-san: We also have one at the hospital reception.
- Wake: Would you please come with me?
- Ishida-san: Yes, I will come with you. I also know the organisers of the cancer support group at this hospital. You can also talk to them. This is something I can do for you.
- Wake: I feel better now.
- Instructor: Please stop there, thank you.

Surprisingly, my performance stood out so that some others overheard our session. A woman from another group said, "I could hear you well even in my group! I see you did some very realistic acting (*hakushin-no-engi* in Japanese). Ha ha ha. You are a good actor!" She and others seemed quite impressed by my performance, especially by my acting ability. Although, to be honest, I did not feel I was merely acting. I actually felt anger during the role-play. I was puzzled by the emotional experiences I felt throughout. What had just happened to me?

At first, I felt I was merely acting the 72-year-old man, but this sense of acting became blurred as our conversation went on. When I checked my performance on the recordings with the information written in the scenario, I noticed that my performance went in a different direction to the one I was supposed to follow when I started to talk about the communication difficulty with the doctor. I remember starting to feel the anger rising in me. It could be as simple as emotionally getting into the role, because I was trying to emotionally associate with the character. However, when Ishida-san started to interact with me, the dynamics became complex. For instance, I felt annoyed when she cut me off in the middle of me telling her something very important. I thought, “Why is she talking about her odd doctor while I am still speaking about my doctor?” I expected her just to listen to me. Therefore, I too cut her off while she was speaking. When thinking carefully about it, this is the sort of behaviour I would look to avoid if I was having a conversation with an older person like Ishida-san in everyday life, because I would be afraid of coming across as impolite and disrespectful. Of course, I knew that she would tolerate my rudeness because she knew that I was acting. Yet, I was not thinking so strategically, but driven by genuine anger. Afterwards, I became even angrier when she asked me questions which I thought were meant to try to shift the focus away from what I was saying. However, at some point my emotions changed from anger to being emotionally touched. This dramatic shift came when Ishida-san said to me, “Yes, I will come with you” in regard to visiting the social workers at the hospital. I felt hope from the way she agreed to come with me. When I said, “I feel better now,” I meant it.

Though years have passed, the profound feeling I experienced has not faded. I remember how safe, reassured, and connected I felt with Ishida-san. Although I was still not sure how to make sense of my own role-play experience, I knew that somehow our different worlds had merged and that it was possible to be understood and have my voice heard. I went back to the recorded material from that day. I listened once again to what we said and how it was said, both during and after the role-play.

In the recording, I noticed that I was persistently talking about the fact that “The doctor did not listen to me!”, my voice coloured by my anger. When I checked this



phrase against my scenario, I realised that it was not something that had been written down for the role. Is it possible that I was expressing my anger from my relationship with my oncologists? When I started to reflect on the encounters I had with different oncologists, I felt angry when I remembered the meetings with my American doctor. First of all, my English skills were so poor that I simply did not know how to ask the questions I had. Years later, when I told my cancer experiences to my wife, she reacted strongly to the fact that I was not offered an interpreter in such a serious situation as when one has to deal with cancer. In addition, they seemed to show no understanding of cultural differences in how one handles a personal crisis. She made me think that things could have been easier if I had been helped to get the right support, and it made me both sad and angry. In addition, what also made me feel angry with my doctor was not his attitude while listening, but his phrase “easy to treat”. With my limited English skills and my Japanese attitude of accepting what was said, the phrase stopped me from even trying to ask all the many difficult questions I had and which I wished I could have asked during the process. Instead, I tried to and thought I had to handle this by myself. However, despite the doctor’s assurance “easy to treat”, and all my efforts, the cancer came back after five years. Some *sempai* in Ippo Ippo also asked me why I did not join a support group in the US, where the group coping strategy is strongly advocated. Again, there was no guidance for such an option. I felt that my American oncologist’s hope, “easy to treat”, prevented me from seeking more practical and effective emotional support. This would most likely have helped me with the strong anxiety I struggled with in the years that followed and which have had a great impact on my quality of life. When after the role-play I took time to look into my anger, I felt that many things could have been done differently.

These reflections led me to see how the additions I made to my role as a 72-year-old man was not based merely on fictive ideas, but was something deeply rooted in my memory from a particular time which apparently was still full of wounds. Maruška Svašek (2005; 2014) would call the rage elicited during my roleplaying as “re-experienced emotions.” She writes “[R]e-experienced emotions are past feelings that are remembered and re-experienced in the present” (p. 200). From that perspective, my roleplaying with Ishida-san turned into a complex interaction. For instance, when

I felt as though my anger was fuelled because I thought she was cutting me off with her husband's episode, the real reason was probably that I felt I was about to lose my opportunity to talk about my experience. It made the target of my anger shift from my American doctor to Ishida-san. It could be that the re-experience of past emotions was getting doubled up through the interaction with Ishida-san.

I became curious about the moment I calmed down, especially since my anger was so strong. It happened when she told me she would come with me to see the social workers. She gave me hope that I would not be left alone. It reminded me of the counsellor in the US who said to me in the first meeting that he could help me (see Section 1.4). So few words, and such a big effect! When thinking about it, although I have visited several hospitals related to my cancer, I never met anyone like Ishida-san, who just listened to me, introduced me to a proper service where I might get some extra support, and most importantly, said she would join me on this path. She was like a friendly companion who would come with me in the strange world of the hospital, where I never felt at home. It is interesting that I describe it as I was listened to, not the 72-year-old man, underlining again that beneath the surface I was indeed talking about my own experiences. Also Ishida-san seemed to be using herself in the role-play. She was not just following the techniques taught by the Peer Support Programme, providing me with empty words made up as a result of communication training. She was doing things just as she had always done in her volunteer work.

This understanding was confirmed through following Ishida-san's everyday volunteer work in the O hospital. For instance, in the O hospital there is a consultation desk where a patient can go and ask for more information about social workers, and she really knows the organisers of the cancer support group. In the role-play, she was friendly and compassionate towards me, just as she is with other people, patients and staff (see Figure 34).



Figure 34: Ishida-san (left) is having a conversation with Yamazaki-san at O hospital, 2013. Photo by Shotaro Wake.

Through the role-play I had the opportunity to experience an imagined scenario, namely what it would be like for me if I were to receive cancer treatment at the O hospital, and had a chance to talk with Ishida-san. I got a glimpse of how it would be to ask the questions I had, to be offered guidance and support, opportunities that had been lacking in real life. Therefore, when she said, “Yes” to my question, “Would you please come with me?” it meant something to me. This seemed to be the “meta-level layer” of my role-play with Ishida-san.

There was still something I was not sure of. Why did my strong feeling of being touched only come with her and not earlier? Since the US, I had had many good experiences of being able to disclose my deepest feelings to people whom I really trusted, like Hedvig, and some close friends and family, including professional counsellors. Furthermore, I also had a hard time understanding why my anger came out so strongly to a person I did not know well and even in a public context. When I discussed this matter with Hedvig, she had an interesting insight: it was, in fact, *the first time* I expressed these troubled feelings and received an empathic response *in my mother tongue, Japanese*. She seems to be right in that in all the situations where I had disclosed my feelings deeply in the past, it had always been in English. Even with

my parents, some of this crucial talk happened in English because my Swiss mother is more fluent in English. Speaking in one's second language is never the same as one's native tongue. Verbal expressions are significantly reduced. Also, when speaking in my own language I tap into the cultural norms and codes that I am so familiar with. I know how to behave and what to expect from others.

At first I was not sure that this emphasis on language was very important. Already at the time of my first fieldwork in 2009, joining Ippo Ippo, I was open about my cancer, and had on many occasions talked about my experiences in Japanese. However, thinking back, at no time did I talk emotionally about my story. I said things like "it was a very hard time because..." but I was not telling them how it felt emotionally to go through that difficult time. Like Okamoto-san, I also found myself not feeling comfortable enough to talk emotionally in front of elderly women. This helped me understand how role-playing enabled me – it allowed me to vent out my relived emotions through the fictional character and his situation. From this perspective, it was actually my real life opportunity of receiving emotional care in Japanese, which would have been difficult because Japanese social codes would have put limits to what I could say and how.

This episode gave me the chance to explore the possibility of creating understanding between the patient and bereaved families through reviewing the recordings of our role-play. Although Ishida-san has many years of experience, it was not easy and straightforward for her to take care of my feelings. Throughout our conversation she approached me indirectly, as is the norm in Japan, and although she never fully grasped the total picture of my mind and sometimes misunderstood me, she did not give up on me, and stayed with me until I felt better. In addition, she was neither discouraged nor angered by my responses. I can see that she continuously participated with me, not at the level of language, but through her attitude and good intentions of not allowing the person in front of her feel alone. Reflecting on this episode with Ishida-san, I realised that the experience of not feeling alone was an important element in furthering my acceptance of being in continuous liminality. Thus, it did not matter whether our different worlds could be shared or not. It was the feeling of not being

alone that mattered. And the way I received this feeling, and also gave to others, was the ability to stay with the listening – both to the silence and to the spoken word.

## 6. Chapter six

### *Amendment*

#### 6.1 *Dialogue with my examiners*

“Shotaro, what is the meaning of the mask?”, this was the opening question I was asked by my examiners, which spurred a discussion that led to this chapter. Continuing the discussion on the mask, they encouraged me to consider the question of how my filmmaking was affected by my cancer experience, seen in light of the Japanese concept of *ma*.

As a backdrop to this chapter, I will explore the combination of auto-ethnographic writing and observational filmmaking. Specifically, I will look at how my filmmaking approach has been shaped by my cancer experience and Japanese cultural background. This is demonstrated through my awareness of the issue of visually representing people suffering in silence, and my playing with the notion of *ma*, the “in-between” in filmmaking. I will then dive deeper into the meaning of the cancer mask. What does it represent, and how can it link individual experience to cultural representation? Thirdly, I will expand the focus of my personal and professional experiences to larger issues around well-being and attentive listening. Finally, I summarise the above by discussing how auto-ethnographic writing and observational filmmaking have helped me in my journey in the worlds of cancer, both as a researcher and filmmaker. After all, what does it mean to look at life through a cancer mask?

##### 6.1.1 Shifts in my filmmaking approach after my first cancer diagnosis

Being a person who concealed his cancer from his own family, and even from himself to some degree, I ended up writing an auto-ethnographic account of my cancer experience, opening it to a wider academic audience. Without using auto-

ethnographic writing as my companion, I would have remained within my cancer narrative more or less in the way I was familiar with, strengthening the worldview attained in this continuous liminality. Furthermore, without making an observational film and using it as a reference for writing, my writing would be a thin description based only upon memory. Through the two methods I was able to step out of my own story and find a connection with other stories into the self. By understanding other people's stories, my own became rather *typical*. Indeed, according to Meneley and Young (2005), this is the key to good auto-ethnographic writing (p. 12). Losing the uniqueness of one's narrative opens up for new interpretations by pointing at things otherwise taken for granted. Indeed, it was through auto-ethnographic writing that I first became aware of the radical changes that had taken place in my worldview over the thirteen-years, which have also affected me as a filmmaker. I started to make films some time after my first cancer treatment, about thirteen years ago, and the changes in my filmmaking approaches could be compared to the shifting relationship to my own cancer. Kierkegaard wrote, elegant in its simplicity, "life is lived forwards but understood backwards", which Irving (2017) expanded on, writing that "It is only retrospectively that we engage in a process of narrative reconstruction whereby a structure is imposed on the world from a position of hindsight" (p. 39). At first, I thought that by looking closely through my films and at their *form*, I would be able to see a red thread in my narratives that revealed how they were affected by my cancer experience. However, it was not that simple. I could see that my film approach then was to rely on my own aesthetic vision, without being fully aware of how my vision was shaped by not only by my cancer experience but also by my Japanese background, contextualised in everyday life and through learning and practicing filmmaking. Referring to Lawler, Irving writes that life is "both lived and understood forwards and backwards in a spiral movement of constant interpretation and reinterpretation. People constantly produce and reproduce life stories on the basis of memories, interpreting the past through the lens of social information and using this information to formulate present and future life stories" (2017, 39). I began to understand through my auto-ethnographic writing and film work that my own storytelling was not linear: if I did not dare to look into my own cancer experience, there would be no shift in my understanding and no shift in my research approach.

My early fictional films as an undergraduate of film studies did not deal with cancer at all. It is understandable in one way since my own cancer experience was taboo to me back then, and I kept it secret from most people at school. However, after reviewing my earlier works I see that my cancer experience cast a heavy shadow on the way I made these films, especially affecting my use of *ma*. According to Cox (2007), *ma* can be translated as an “interval” in space and time or the state of being “in-between”.

“It is a transferable quality of visual and material expression which those who choose to work in any of these diverse media must invariably learn through a singular educational system based on observation, imitation and constant repetition” (ibid, p. 1).

Indeed, film as a medium is suitable for aesthetically expressing *ma* because it allows the filmmakers to manipulate both spatial and temporal possibilities through filming and editing, thus achieving a sense of an authentically “Japanese” aesthetic vision in their films. I see that in my earlier works, I thought of *ma* only in terms of aesthetic codes, and not through other domains such as the realms of subjective experience, the relationships between persons, and metaphysics such as the void (Nitschke, 1988). Indeed, the ambiguity and vagueness inherent in *ma* provide plentiful potential in creating meaning in the space between two things. According to Pilgrim (1986), “[*m*]a seems to operate at, cross, and even deconstruct a number of boundaries” (p. 257). The more I learnt about myself and my mistakes as a filmmaker, the more I wanted to move away from the aesthetic role of observer that I felt maintained boundaries and a lack of understanding with the filmed persons. I wanted to deconstruct these boundaries so that I could enter into the same *ma* as the filmed person. Nevertheless, in those early years I blindly believed that my own artistic intuition and vision would do the job in producing original films, while positioning myself unconsciously in a way typical to Japanese films: I gave the actors little dialogue, directed them to express their emotional pain in silence, filmed them using long takes, and edited them into slow paced final products. I seemed to imitate the style of the Japanese “distant observers” (Bruch, 1979) like Ozu and Mizoguchi. By



reading Cox (2007) I became aware of how my imitation guided me to use the notion of *ma* in a more aesthetic vision of filmmaking.

Despite this, I noticed that there is also something authentic and personal in my films. For instance, in two of the films the male protagonist seems to struggle with personal issues, which they deal with alone. They remind me of my own attitude towards my cancer then. The absence of cancer in filmmaking was the presence of my cancer shadow. This dynamic could have been a good use of *ma*, a way to let the viewer know about what is not there, but only if this use had been conscious. However, I was only ready to creatively use my cancer experience in filmmaking by incorporating it through Japanese aesthetic codes, and I missed its wider potential for visual ethnographic research.

My idea of filmmaking began to change as I became conscious of the issue of visual representation. I felt uncomfortable finding myself a subject of the stereotypical cancer patient, and I saw how people in Ippo Ippo were also concerned about the way the Japanese media, including filmmakers, either represented cancer patients negatively (*dying* well), or overly positively (*living* well). One member told me, “I wish I could recommend others a film to watch about cancer patients, but (I do not feel like I can because) they all die at the end”. I had barely paid attention to visual representation when I made my fictional films. I was only concerned about the images of my characters in terms of how “I” as an author thought they would look in “my” films. I did not treat my actors as collaborators but as people whom I needed to direct to express my aesthetic vision, which would help me shape a perfect, harmonious story.

According to film scholar Bringham (2015), many Japanese mainstream and documentary filmmakers have used themes of illness, disease, and handicap to dramatise their stories, often highlighting a character’s heroic death or their sufferings as victims.

“In many cases, it is not illness *per se* that animates the films but a figurative sense of people at the mercy of something much larger than themselves over which they have no control” (ibid, p. 150).

The problem is that people with illnesses are reduced to mere emotional icons for drama - they *mean* something for the purpose of structuring the narrative so that the filmmakers can convey their own voices and aesthetic vision. Such filmmaking practice is hardly an empathic and empowering way of visually representing people afflicted by cancer. Ironically, I was one of the filmmakers who created these stereotypes by counting on my own aesthetic vision. It shows that the use of *ma* can easily become a way of only displaying a form or style, or something fixed like a stereotype, while the complexity of the human being is reduced to that of an object by putting the focus only on its aesthetic codes. I know today that better visual representation gives more control to those I work with in filmmaking. Nevertheless, it was challenging for me to find a balance between what and how these filmed people want me to show and tell their lives compared to how I wanted to present them.

At the time of *Ippo Ippo*, I was not skilled enough to look for a narrative that differed from my initial plan of following the Mt. Fuji event. However, a seed was planted to collaboratively work with the filmed person(s) to explore our mutual interests following unplanned everyday situations, such as the one that took place during the tennis sequence. Thus, when making *To the Last Drop*, I wanted to attempt a more personal narrative. I was inspired by the documentary films of Makoto Sato<sup>10</sup> who, through filmmaking, developed heart-warming friendships with people suffering from serious illnesses and handicaps. Yet I wished Sato had showed more of how the illnesses were ever-present in their everyday lives. What is the appropriate way of handling emotionally sensitive matters related to illness in a film? Like Sato, I did not want to tell their story based on formal interviews. TV documentaries often construct their narratives based on highly organised interviews. However, I do not believe Okamoto-san would have said anything personal to me in the kitchen if he had sensed I was trying to interview him after he had disclosed his bad news. Instead, our talk in

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<sup>10</sup> For instance, see Sato, Makoto. 1993. *Living on the River Agano* (Aga ni ikiru)

the kitchen turned out to be “a real conversation during which different points of view can eventually be confronted” (Piault, 2015, p.172). What made this possible?

With a no-interview line, I had to shape my observational filming style into something more conversational, toward being playful, spontaneous, and casual. My style, then, was a response to the approaches of documentary filmmakers and classical Japanese filmmakers. For instance, I used a mobile phone as a filming device, and combined it with the method of “feedback screening”, a technique that fascinated me in the films of Jean Rouch and Morin<sup>11</sup> and their playful spirits (Feld 2003). Later I also used this technique in editing. The mobile phone freed up my face while filming and allowed me to have frequent eye contact with Okamoto-san, while also allowing him to see my facial expressions. It enhanced our sense of mutuality, intercorporeality, and thus our intersubjectivity - I could concentrate more on our conversation as well as allow myself to feel more during filming. In addition, filming our conversations while holding feedback screenings on the computer allowed me to come in as a character while watching film clips so that I could film the process of how we collaboratively shaped our mutual interest – the tea service – through our conversations. This again sculpted the film narrative. Through feedback screening, I became aware of sensitive issues under the surface, in the realm of silence, particularly in the relationships between Okamoto-san, the group members, and his wife (and daughter), and I had to balance the norm of silence and bringing out sensitive issues while editing. For instance, I learnt that Okamoto-san’s wife seemed to be the only person who could openly give a critical comment on Okamoto-san’s tea service. Although I knew he most likely would not encourage this, I believed that it was important to include her voice to avoid making him into a conventional “samurai” hero who bears his suffering alone for the sake of his wife. However, I sensed that his wife was not comfortable showing herself in the film. How could I include her and still be sensitive to both their wishes?

To overcome the issue, I also played with the notion of *ma* during editing. By only including his wife’s voice together with the scene of the feedback screening at their

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<sup>11</sup> Jean Rouch and Edgar Morin “Chronicle of a Summer” (1960)

home, I created an ambiguous temporal layer around the chronological narrative of Okamoto-san's tea service, which both reveals and preserves what is hidden behind the silence. By letting his wife talk for him, I did not have to interview Okamoto-san. By letting him talk about his wife and her health, his wife remains invisible and silent about her health issues. By handling someone's comment on one end and someone else's silence in the other, an interval could emerge between the two: between what is said and what is not. This approach is sensitive to the traditional value of silence, and makes use of the traditional idea of *ma*, of how the sense of absence nourishes the sense of the present. Approaching Okamoto-san in this way as well as including him in the filming process was, I believe, a crucial aspect that not only enhanced the sense of trust between us, but also allowed us to have the kitchen talk where *ma* moved from only being the space we shared, to being a place where we could sense each other.

#### 6.1.2 Life with a cancer mask

People in Furatto were sensitive about the differences between our cancer statuses, a view that would separate us from sharing the same *ma*. However, when looking back, I see that we could have found a common ground in the cancer mask, a mask I at first thought was only worn by cancer patients, shaped by the experience of existing in a continuous liminality. This mask, I argue, is quite distinct from the everyday masks described by Goffman. Goffman (1959) argues that a person wears a mask when he interacts with others in social situations. Each mask enacts a role that is appropriate for the occasion. What is appropriate is something often taken for granted in a culture, and it is a social skill to know how to smoothly shuffle these masks according to whom the person is interacting with and the situation. For Goffman, a "mask represents the conception we have formed of ourselves – the role we are striving to live up to – this mask is our truer self, the self we would like to be" (ibid, p. 19). However, I would argue that the mask related to illnesses, especially serious conditions such as cancer, differs from other kinds of masks – in particular because it is not a mask you can decide to put on in certain situations and not in others. To the wearer it is irremovable as it represents the high awareness about one's own cancer. The cancer mask is shaped

by life in continuous liminality – the wearer feels as though the uncertain condition with cancer is not over, while people and the world around seem to continue in the same way as before. To many cancer patients, the sense of a familiar place in the world seems to have been lost, but they still remember how things used to be. This feeling of a gap seems to be elicited by the fact that one cannot fully recover the state of being before being diagnosed with cancer. For instance, my confidence in my health has remained fragile since the first diagnosis over 13 years ago. The writings of Drew Leder (1990) remind me that what I have lost is this taken-for-granted-ness about my own sense of health in my body. Indeed, being healthy with a sense of well-being means that a person can count on the belief that illness is only an occasional experience which will end shortly, rather than thinking of it as a chronic condition. Thus, the cancer mask should be viewed as a chronic mask, something very distinct and visible compared to other everyday masks. The wearer needs to get used to it in every situation while learning to live with what has become their “truer self”, to increase the sense of acceptance and familiarity in times of ongoing uncertainty.

However, it takes time to get used to living with the cancer mask. The wearer needs to find out whether showing the mask to others is a wise decision or not in terms of living in the world of the healthy. No wonder many have concerns about losing head and facial hair due to treatment because then the cancer mask becomes clearly visible to the self and others. The possibility of hiding disappears, and this is uncomfortable for both parties – that which is supposed to be “private” becomes “public”, and the private self is recognised by others as the dominant character. This is problematic to a Japanese person as, in the context of Japan, a sense of self-worth depends on the ability to occupy multiple social positions in an intricate hierarchical system, and to be able to shuffle identities depending on whom he is interacting with. Therefore, being fixed in one entity could be troublesome for Japanese “relational selves” (Rosenberger, 1992; Bachnik and Quinn, 1994). For instance, I rarely expect a serious or honest answer from an ordinary everyday greeting such as “Ogenki-desuka?” (“how are you?”). It is merely an opening phrase. But when I meet someone who knows about my cancer, I become sensitive about how to respond to this same question. It can potentially complicate the encounter, and carrying around such a

possibility makes me more nervous. Thus, concealing cancer or being silent about one's own cancer in social relationships if the signs are not visible is an easier and safer strategy so that one can save face and avoid social embarrassment (Frank, 1995).

Concealment as a strategy may preserve relational selves in everyday life, but to pretend everything is fine when in fact it is not enhances the feeling of isolation. In addition, it creates a discrepancy between the presentation of self and how the person with cancer actually feels. This incongruity may increase the awareness of one's own cancer mask, which again builds up under isolation and thus reduces the quality of life. As hair grows back, and a person's physical appearance returns to the way it was before, they are again able to decide when to go public or stay private with their mask. However, an existential experience such as cancer does not simply disappear with return of a 'normal' physical appearance. The awareness of one's own mask often remains, along with the belief that one is always onstage in public and judged by those around, even though these people may not know there is anything to judge. A person's own expectation of how the culture will treat him may thus be an important issue to be dealt with. This requires letting other people empathically contest whether one's personal view about their cancer fits the cultural understanding of cancer. However, with concealment to avoid potential judgement and feelings of fear and aloneness, one may miss the opportunity to receive such empathic understanding from others.

At the same time, it can be exhausting to open up freely to the public, because the individual with the cancer mask is put under a spotlight as the leading actor on stage in the local world of the healthy, including doctors and health professionals. In contrast to Goffman, who took a spectator's view to the actors on the stage, my account shows what it is like to be the lead who needs to carry on with the show, and who is applauded based on whether the show is good or not. Though each show differs, the lead actor feels as though the audience expects him or her to find a way to have a meaningful life, and to be thankful for this discovery. For instance, decades ago in Japan when there was no effective treatment, the cancer patient needed to meet the expectation of 'how to die well' by doing something meaningful before their death. Today, as there are more treatment options and survival rates are increasing, the norm

has become more ‘how to live well with cancer’. Despite changes in society, cancer patients still need to perform *well* in order to demonstrate to themselves and their audiences that their lives are meaningful, thus making their pain more bearable for those around as well as for themselves. As a person with lived experience of cancer and who has studied how other people with cancer live in Japan, I cannot underscore enough how exhausting it is to live up to this. Would it not be easier to live in society if persons with cancer masks do not have to demonstrate to others that now their lives are really meaningful?

### 6.1.3 The quest of well-being: attentive listening for those behind the cancer mask

When a person no longer fits or lives up to the ideal model of what the culture constitutes as healthy, this person has to find meaning and acknowledgement through other means. This is not easy as illness often sets an existential crisis into motion, questioning what a meaningful life is, their personhood and the situation. Furthermore, both the definition and the experience of illness are affected by culture, and this again affects the understanding of the self. An implication of this is that one’s cancer identity will change one’s relationship to the culture. It is a lonely journey searching for a meaningful life beneath the shadow of a healthy culture in which the traveller no longer feels he belongs. In the darkness, it is difficult to find paths back to a life of well-being which contains a basic trust in one’s own health and to see who else is out there. And the more one ruminates about existential worries, the less one progresses, and the more alone and away from others the traveller feels. When finding yourself in a state of remission, not knowing if or when your cancer will come back, is it possible to go on “the quest for well-being”? (Stoller, 2014, p. 140). Stoller argues that we all desire to increase our well-being, but that this desire also makes us restless. In his previous work (2004), he writes that the road to well-being does not go through wanting to be the same as healthy others, but through cultivating an acceptance of the uncomfortable state of being in the place “in-between”, where one neither belongs to the village of the healthy nor to the village of the sick.

My experience highlights that this acceptance seems to be cultivated through listening attentively to my own existential questions with the help of loved ones and counsellors. Listening is about one's own willingness to face and commit to emotionally difficult issues that are co-present in the same space and time. Often with illness, these existential questions become very noticeable, and are centred around one's unavoidable misfortune in life and a feeling of isolation. Yet, seeking answers to questions that do not have a fixed answer makes us restless, and being in that state also makes it difficult to listen to the questions of others. A crucial shift for me came when I learned to listen attentively to others in the support groups. Through listening and talking, people are able to create interpersonal relationships (Matsunaga and Gotay 2005). Through this process, my self-centred narrative began to orient itself outwards and to see connections with others. I became curious about their masks, and I felt glad that they wanted to know more about me as a person who also had a complex role in society. Through this I was stepping down from the stage as a lead actor, so that cancer did not have to encompass my dominant persona and the expectations that come with it.

Instead, as in Stoller's experience, the lead actor can begin to play the supporting roles, and shift from storyteller to listener, to co-teller and co-listener. This was exactly what took place in the kitchen scene with Okamoto-san. My presence, though I did not say much, seemed to help him ground himself in the present, away from anxiety and worries. Such worries tend to orient thinking toward a negative future, since what awaits one in the future is ultimately death. They are the expression of the metaphorical thinking: 'cancer equals death'. One may say that thinking of cancer in these terms seems to accelerate one's sense of time since it constantly reminds one of its limitations. It urges the person to engage in the present as though one has to do something meaningful now or never. This is hardly mindful. I suspect that this sort of temporal urgency is built up by a sense of restlessness, which reduces the overall sense of well-being. However, being present through attentive listening in the same space with Okamoto-san appears to help him ground himself in the present too. It means his sense of time is also slowed down, and he seems to become more aware of his surroundings. This is illustrated through how he gradually adjusts his focus from



talking to me about the future to about preparing the tea in the kitchen right here and now. In line with this, one can say that both Ippo Ippo's Mt. Fuji event and Okamoto-san's tea service have a similar effect of decelerating one's own sense of time by calling attention to one's bodily sensations through climbing, seeing, smelling, and tasting. This change in the sense of temporal urgency is I believe caused by how their activities are based on different metaphorical thoughts, such as 'live well in remission'. This is powerful because according to Radley (1993), this sort of shift in metaphorical thinking is not just about thinking differently but suggests a paradigm shift from one channel to another, and in this context, the path towards a better quality of life. Being co-present here and now is thus one way of facing one's own and another's cancer mask, and countering the feeling of isolation that otherwise separates us from each other.

#### 6.1.4 Wrapping up – lessons learnt from the cancer journey

The auto-ethnographic journey has been a bridge between my personal and professional selves. My cancer journey has brought me through lands of avoidance to acceptance, from deafness to listening, recognising myself in others and others in myself. Just like Paul Stoller caught my eye through his cancer mask, I could start to recognise the presence of others in my own narrative and feel more reassured and connected, thus reducing the feeling of isolation in my life within a continuous liminality. The journey allowed me to see my cancer mask not simply as a limitation but rather as a resource for creating meaning and thus well-being. I believe that the mask has shrunk in size, probably to the level of my other everyday masks, so that I feel freer to juggle between them in different encounters and social situations, and accept the mask as a part of me. Looking at others through this cancer mask is no longer scary because I have learnt that the experience of good eye contact through the mask can change the doomsday scenario in continuous liminality, even if this remains temporary. This understanding has become possible due to much scrutinising of encounters and personal and professional experiences through a combination of auto-ethnographic writing and observational filmmaking. I have found that thinking in terms of *ma* has been helpful in approaching sensitive matters, allowing me to keep

focus at a sensorial level which is helpful, I believe, not only to the anthropologist and the filmmaker, but also to the people we meet.

When showing *To the Last Drop* to Okamoto-san for the first time, I was afraid that I revealed too much about the things he kept silent, but he was quite happy about the result. “This is exactly what I often feel I want to tell other people about!” By using the strength of each medium, both filming and writing, I was able to present a broader understanding about the experiences of people afflicted by cancer. Together, they expand on *ma*, where suffering becomes visible and silence becomes audible, in a culturally sensitive way.

## *7. Chapter Seven*

### *Epilogue*

#### *7.1 Conversations with my Norwegian Oncologist in my Recent Check Up*

Now at the end of my journey, let me disclose an episode from my most recent health check-up and conversation with Dr. Elvestad. The readers may see that I have a somewhat different attitude to and relationship with my current Norwegian oncologist (not the doctor in Tromsø, but the one in Oslo who has been my doctor since I moved here) compared to the previous ones mentioned in the thesis. In addition, the following episode reveals a few things that broaden my understanding about issues discussed in my thesis.

Dr. Elvestad had been my oncologist for years before Hedvig and I had our first child in 2014. On the day of the recent check-up, we were waiting to be called in. Hedvig was reading her magazine, and seemed to be relaxed as she always is. “There is nothing to worry about since you are not going to have an ultrasound this time,” she said. But I had already been nervous for a week, which was not too bad compared to a couple of years ago when I could worry for two months before a check-up. It may be that being extremely busy with my thesis helped distract me from worrying. I was sitting still, trying to remind myself to take deep breaths, although I always find it challenging to do so at the oncologist’s office. I wished the check-up could come after my thesis submission, but I also knew that I would feel great after passing it. I know I was anxious because I had diarrhoea, and most likely I would need to rush to the toilet after the consultation.

Dr. Elvestad shook hands with each of us as a way to welcome us into his office. This is how he always greets us. I recall he once told us, “My colleagues seem to think

it is strange that I shake hands with my patients.” I imagined Dr. Elvestad might be a bit formal, since as far as I knew, Norwegian people tend to shake hands only when they meet for the first time. But, having grown up in Japan, this formal approach suited me quite well. It is not because Japanese doctors greet their patients with a handshake – I do not recall shaking hands with my doctors in Japan or witnessing others do so – but it is a soothing start, not too formal nor casual, and end to a clinical encounter which might otherwise be more stressful. So, I consider a handshake to be a nice way to frame such a “short-lived liminality” (Crapanzano 2004). By shaking hands, I felt I was being acknowledged as a respectable person, just like anybody else, and was not simply reduced to the role of a cancer patient.

Since I had been busy writing about my cancer experiences, including the passive and dependent attitudes of patients, I thought I could try to open the conversation. I told him how stressful recent days had been for me, finishing my thesis and writing about my time in the US and Norway. Then, I asked him a question I first thought of after taking the autoethnographic approach in my thesis, “When I think about it, it has now been 13 years since I got my first diagnosis, and six and a half years since the second one. When do you think I can leave this behind? Will there be a day when I will be all right with this?” Dr. Elvestad thought for a moment before he answered: “It’s difficult for me to do something about the way you are thinking. Since you are writing about it, you keep it fresh in your memory.” I see! In this sense, as long as I am staying within the field of the medical anthropology of cancer, I am actively exploring my traumatic memories. In this case, I had better make use of it, just like Stoller. Rather than avoiding it, he genuinely invites his readers to take part (2004, p. 203):

But once you’ve got it, so to speak, why not incorporate it, as the Songhay would say, to bring to your being a deeper understanding of life’s forces and meanings? Cancer can be used, and my example is one of many thousands, to grow and change. It can show you how to fly on the wings of the wind.

The view from the wings of the wind turned out to not be as scary as I used to think. By embarking on an autoethnographic journey, I could let these fearful memories

breathe, so to speak. I could change my academic attitude to look attentively at them, and then to critically and constructively examine them, and hopefully turn them into useful knowledge for other people. Having a casual conversation with Dr. Elvestad was one of the positive outcomes of this writing process.

In fact, our conversation gave me great inspiration to understand how Norwegian oncologists could instil hope in their patients. I could not find any good literature about this topic written in English, although there may be some in Norwegian. I do not recall anything particularly “Norwegian” in the way my first Norwegian oncologist communicated with me at the time of receiving my second diagnosis. I remember he told me they still thought they could cure my cancer, and I somehow felt soothed looking at the pictures of the mountain on the wall of the office (see Section 2.1). I thought his attitude was similar to my American oncologist’s, but the new inspiration came to me when my conversation with Dr. Elvestad turned into a cultural preferred way to communicate topics related to cancer between oncologist and patient.

He told me he knew of a study showing the different responses between Italian and Norwegian men after having their prostate gland removed due to cancer. I am not sure if I remember the study correctly, but the basic point was that two groups of men had the same disease and the same treatment, but they responded differently and sought reassurance from the oncologist in different ways. For instance, Italian men preferred their doctor to talk about the possible consequences on their sex life, while the Norwegian patients preferred to hear about its consequences on physical activities such as skiing. “And,” Dr. Elvestad added, “on chopping wood. That is what my patients often want to know. I have to talk a lot about skiing and chopping wood.” Chopping wood! It reminded me of one of Alan Radley’s episodes (see Section 2.4), where Canadian men, after having been hospitalised with a heart attack, seemed to want to demonstrate to their wives (and the researchers) that they were still capable of doing physical activities like chopping wood. This is how they find hope, so that they can continue with their lives in the way they used to.

What I now understood for the first time was that my cultural background might somehow have made me miss receiving hope from my oncologist in the way he intended to give it. The doctor did not talk anything about skiing or chopping wood to me, because he was probably not sure I was interested. I did not ask him questions related to this topic either. Also, my age, my student status, and my limited Norwegian language skills probably made him assume I did not own a mountain cabin, *hytte*, where many Norwegians spend their holidays and do daily activities such as skiing, hiking, and chopping wood to make a fire for the *hytte* or for grilling their meals in the open air. Along this line of thinking, the photos of the gorgeous mountain on the wall may have a much more powerful influence and give more inspiration for Norwegian patients, especially in a city like Tromsø, surrounded by beautiful mountains. This episode seems to me another example of the cultural clashes I experienced in my doctor and patient communication. The doctor may have hesitated to be empathic in his usual way and/or I may have missed recognising his empathic expressions. Thus, the way the oncologist instilled hope took a universal approach, such as discussing the matter with me at an existential level, of whether I could survive or not. This sounds drier, more direct, and more anxiety provoking to me compared to discussing the same matter through topics like skiing or chopping wood.

After Dr. Elvestad had examined the lymph nodes around my body as part of his regular routine, and told me everything seemed fine, he asked: “How long was it since you had your last treatment in Norway?” I reminded him that, “It’s been six and a half years.” “I see. The second time has passed the first five years.” For the next regular check-up, he decided not to order an ultrasound (CT scans were stopped a year ago) and said that he might consider seeing me only once a year. I felt good, as I was now about to enter into a new phase in my cancer journey. I was taking another step towards moving away from the time of the treatment. At the same time, I was a little anxious about the fact that from this point on I had to rely on my own bodily sense of health, and will have to know from my sensations and condition if the cancer has returned (or a new one emerged). Up until now, medical technology could detect it at an early stage through regular check-ups.

Dr. Elvestad said to me, “It is important not to look into things too deeply.” He continued, “This is true not only for you, but we as oncologists and persons, we need to remind ourselves to trust our own sense of body and health. We have too many things we can measure these days, finding things that are unnecessary. People have many things in their bodies if we look too closely.”

I liked this phrase at once: *To not look into things too deeply*. It was my new favourite phrase. It was a good reminder for me when writing in the autoethnographic form, to move closer, but not too close to obsess about it, which enables me to see others from just the right distance.

## 7.2 Letting Others Take Part in my Cancer Journey

A month before submitting my thesis, while my wife Hedvig was reading my manuscript, she said to me that writing about my own cancer experience worked as an exposure therapy for me. I thought this was a bright idea, and started to think if I should reformulate my thesis from this perspective. Indeed, I found there were some scholars who had recently published articles from this angle (for instance, see, McMillan, C. and Ramirez, H.E 2016). What I had forgotten about myself is that I tend to take things literally. Later the same evening, Hedvig clarified that she did not mean to encourage me to take this approach at all, especially not in this extremely stressful situation, as the deadline for final submission was approaching, and every family activity had to be downgraded in favour of, as she called it with some frustration, “your paper.”

What Hedvig meant to tell me was that through writing my paper, I dared to face my past. She is right about this. As I went on writing, I started to remember things that had been long forgotten – my student life at a local community college and UC Berkeley, which led me to recall memories related to my counselling experiences. Writing about my first cancer diagnosis led me to reflect on the second one, particularly the critical moment when I received my second diagnosis. These memories came back little by little through writing and through looking through photos from those times.

Especially in the early phase of writing, I felt discomfort about remembering those memories, and I could not motivate myself to write them down. I was frustrated when I thought, “Why do I have to think and write about my cancer experiences all day, every day?” I could suppress those feelings while I was editing my film, *To the Last Drop*, because I could meet Okamoto-san, his family, and others whom I became friends with, and recall the time we were together. I recall that it worked in the same way when I edited my previous film *Ippo Ippo* during my master’s programme. But again, when it came to writing about my own experiences in an autoethnographic form,



my mood dropped. I wished I could write about somebody else's experiences, suffering and pain, anybody's but mine. I also tried to write in the third person, but it just did not feel right. And anyway, such an approach also comes with issues. For instance, when I try to use my films, shot in a participatory observational style, as reference points for analysing and exploring themes emergent in the text, the observational film style and third person point-of-view made my approach look like that of the behaviourist who describes detached, objective reality. It cuts off all complex intersubjective dimensions in communication and interaction between myself and those I am filming. I could only talk about their behaviour and not about the motivations, intentions and feelings behind their actions. From an ethical point of view, it did not feel right either to treat the people I worked with as mere objects of my study. Being treated as an object was the most uncomfortable experience I ever had with my GP and his trainee in the US (see Section 1.1).

As I continued writing, I got used to it, although it took a long time to come this far. I recall very well what it was like for me to write a proposal for my master's programme in 2009. I genuinely felt a minor, yet uncomfortable electrical body sensation every time I typed the word cancer. That was how much discomfort I felt when exposing my cancer patient role to people other than my wife, family and counsellor. Why did I do it anyway? It all comes down to the idea that although my cancer experiences are the source of my deepest fear (which I am aware of), in some strange way I was probably also curious about it.

Yet, I would not consider myself a person who has overcome the illness experience at all. My confidence with respect to health has turned into something fragile and easy to break if I detect any "signs" of cancer recurrence, even today. However, I have also found a great resource to draw from and cultivate through my daily routines. That is my mindfulness practice, based on a programme (the Mindfulness-Based Stress Reduction programme, MBSR) by Jon-Kabat-Zinn (2013). I have practiced dedicatedly every day for almost two years now. I cannot objectively talk about the beneficial effects I may have experienced through this practice, but for me, it is fair to say I can concentrate more on my writing. I am more aware when to take short

breaks or when I feel discomfort from remembering and writing something that approached the anxiety or fear in me. I am also more conscious about my lifestyle, thanks to Hedvig. I eat healthily and do daily exercises – not macho-style as I did in the US, but a combination of conditioning, balance, and strength training. “Lean but physically active and capable” is my new motto.

Still, despite all my efforts and the fact that things seem to be moving in a good direction, my confidence in my health continues to be fragile. In fact, just two days before handing in my final manuscript to my supervisors, in the midst of a highly stressful time, I was suddenly bothered by a phone call I received, but I did not answer. The phone call was from an unknown number and they had tried to call me twice. I got wound up by the thought it was Dr. Elvestad trying to reach me to tell me the bad news after the blood test results from my last visit had become available. I tried to remind myself that our appointment was already over two weeks ago, and he would have called me already if there was anything to worry about. But I did worry, and my body was alert. If this had happened earlier, I would probably have tried to handle it myself, by duelling with my thoughts, but then I would not have been able to concentrate on my studies. So instead, I picked up the phone and sent a text message to my wife. She responded just as quickly (see Figure 35).



Figure 35: Screenshot from Wake's iPhone. Morning chat with Hedvig, 2017.

As shown in Figure 35, one minute was all it took for me to be reassured and regain control so I could concentrate on my studies again. Some may think that my mindfulness practice is not helping much since it could not fix my underlying anxiety. But as Jon Kabat-Zinn (2013) explains, mindfulness lets people cultivate their own awareness about themselves, their bodies, and sounds so they can make a conscious choice to not simply react, but actively respond to things they perceive as threats; not to react in a positive or negative way, but in a more neutral and constructive way. In this sense, I was glad I had sought help from my wife, whom I fully trust, to handle the situation. I do not need to be a hero and handle everything myself. I also feel it

was good use of the idea of “not looking into it too deeply”. This is a good balance for me, and seems to be working.

By incorporating this mindful approach to my autoethnographic writing, small, but still good and precious episodes were coming back to me. Indeed, besides my dark time at UC Berkeley, it was also the time I met Hedvig. I started to remember more about what we did together and how that was for me. Some of these episodes are of when we took as many gym classes as possible, when we hiked up the hill beside campus, and cycled around the town to find a Japanese restaurant. Shortly after my graduation from UC Berkeley, I took a short course at a film school, and we made a small student film together. There is an area with a lake in Oakland where we used to walk and talk. She listened patiently to my cancer story (“You were only talking about yourself”, she might say). These small memories are from when I began to talk about my cancer story to a few select people, and the first time I started to let a few select, little by little, challenge my way of understanding my story. I started to let someone else take part in my cancer journey. I dared to listen to myself as well as to others. This shift was anxiety-inducing, as though someone else was steering my ship, but I am glad I took the opportunity to learn how to let others be empathic to me and for me to be empathic to them.

### *7.3 Concluding Remarks*

My cancer journey started in 2004 and I am still on the road thirteen years later. Although over the years, the paths I have taken and the views I have seen have changed. Writing with the autoethnographic eye has allowed me to trace some of my footsteps through the different cancer worlds. It would be a lie to say that if I got the chance, I would choose this path again. It has been an unquestionably rough journey. At the start, I was not able to listen. I was simply too scared. However, as I began to face my anxiety, spurred by the empathy I felt from those I met along the way, I became interested in how empathy is expressed through listening. I started to wonder how one hears a message that is unspoken? How does one understand suffering that is not visible? With these questions in mind, I sought to explore the phenomenon of listening, from my own cancer experience to that of others, as well as in the role of researcher.

In Chapter 1, I demonstrated that in order for a sufferer to become a listener, the first step is to face their experiences and listen to their own story. To go on with my cancer treatment in the US, I needed a dose of hope prescribed by my oncologist. However, as a young student living away from my family, the dose from my doctor was not enough, and I bought a hope kit from the American cancer hero, Lance Armstrong. This helped me replace the idea I had inherited from the film character, Watanabe: that cancer equals death. However, it only worked while I was fighting throughout treatment. It did not help me afterwards while I was in remission. My counselling experiences taught me that avoidance (Watanabe) or attacking (Armstrong) fuelled more anxiety. Instead, what I needed to do was listen. Listen to myself, and actively seek help from those I trust so I could also be listened to. In Chapter 2, I came to the point in my journey where I tried to approach the field of cancer through the eyes of an academic. With these eyes I tried to deal with my second cancer diagnosis. What helped the most was not the critical eye, but the positive effects of daring to listen to the reassurances from close others, helping me to see I was not alone. Furthermore, I also describe the meeting with Paul Stoller. He introduced to me the concept I have

since called the ‘cancer mask’, and illustrated that even those things which seem most fearful in one’s life, such as living with cancer, can still be used in a constructive way: to understand those who live in the world of healthy and the world of sick by creatively integrating the roles of researcher and cancer patient. In Chapter 3, I looked further into the knowledge I gained from Stoller, and started to consider my own approach for living with continuous liminality. A key approach, again, was listening, and I describe how listening opened my eyes to families and bereaved families whom I believe live under the shadow of cancer patients in discourse and in the practice of biomedicine. In Chapter 4, I describe how listening to families and bereaved families did not come as easily as I initially thought. I was challenged by the idea that their worlds and my world were separate due to our different experiences. I demonstrate how I had to use my roles as researcher and filmmaker to open up these differences. Furthermore, I look at how Okamoto-san and I worked on a project as a team, allowing our differences to be minimised through a *heiso* relationship, so that mutual listening was possible. This is described by analysing a sequence from the film *To the Last Drop* (2016), which I made during fieldwork. In Chapter 5, I expand on the notion of listening, learning that listening can take many forms. I describe three encounters I had during my fieldwork in Japan. In the first encounter, I describe how listening fails when Japanese social norms and etiquette are broken, especially when listening to an emotionally-sensitive topic. In the second encounter, I look at how the two worlds of cancer, belonging to the cancer patient and the family member, can co-exist so that light is cast on the shadow of the cancer patient. This is also exemplified with video sequences from the film *Ippo Ippo* (2010). Finally, in the third encounter, I look closely at how the differences between the two cancer worlds can be minimised. Ishida-san was able to attentively listen to my needs to such a degree that our differences were really minimised, thus making me feel understood. In sum, these three encounters emphasise the possibilities and limitations of listening and understanding.

At the end of this thesis I have come to learn that understanding is not a condition or state of achievement, but a creative, collaborative project dependent upon listening. Listening comes in many forms, starting with myself, accepting not only the words I

had to say, but also the words of others. This required patience and time but along the way relationships grew which were based on deep respect, filling us with a mutual sense of understanding. With friendship too, comes responsibility. Stoller, in his recent work *Yaya's Story* (2013), demonstrated that where cancer is an underlying theme, understanding called for attentive listening as an ethical response to his old friend. This response turned into a long-term commitment until his friend departed from his life. This commitment is something I feel as well. My friendship with Okamoto-san continued after my fieldwork. We have written emails on a continual basis, updating each other on our lives. He has told me how he has perfected his tea service, and although it was interesting to read about his dedication, I also became more and more worried. His wife's condition was not getting better while he spent most of his time alone in group meetings. The project we created together, partly to make him feel more comfortable in the group, was also what hindered him from being with the group. Not only was he my friend, I also felt obligated to help in this situation I in part created. I knew that preparing tea was very important to him and that this was not something one should take away from him. Therefore, I suggested to him and the group organisers that he should begin to prepare tea in the same room as other members. This was not an easy decision for Okamoto-san to make, because it meant losing the sophisticated aesthetic of the tea-serving process that was so important to him, not only at the level of preparation, but in the wrapping of the tea he served. He would for instance have to let go of using a fire to heat up the water and instead use an electrical boiling pot, which makes the water smell a little like plastic and in his opinion, does not look elegant. However, he listened to my worries and took on the challenge. And indeed, he has found a way of refining his tea service in the meeting room. Today, he is visible and audible to others, and importantly, he too can see, hear, and sense the ups and downs that others also experience in their daily lives (see Figure 36 below).



*Figure 36: Okamoto-san's tea service in 2015, two years after the fieldwork. Photo by Shotaro Wake.*



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