

**Cancer From a Spatial Perspective: Locating the
Unspeakable, Healing, and Hope**

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Declaration

I declare that the thesis and the research work thereof represent my work, except where due acknowledgement is made, and that it has not been previously included in a thesis, dissertation or report submitted to this University or to any other institution for a degree, diploma or other qualifications.

Signed.....

(Vicky Wing-kit Yau)

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Abstract

Illness narratives in all their variety have become a central focus of the cultural study of health and disease. These stories inform other patients of what it is like to be living with a certain illness, or about treatment options, or about the possibilities of transcendence. They represent efforts on the part of the narrator to make sense of their suffering from the illness and they thereby promote empathic understanding of the illness experience. However, narratives in general rely on a temporal structure in which each event is located in a linear sequence, and this can limit the way illness is represented, especially in relation to a disease like cancer. The story of cancer is often flattened into some kind of personal history or reduced to a strive-to-survive story. This thesis challenges the dominant linear approach to telling cancer stories and argues that a spatialised account is needed to articulate the wider, multi-dimensional cancer experience.

Drawing on a range of written and filmic texts, the thesis is an attempt to free cancer from the temporal plot. Even though this is a cultural study of cancer, it is not concerned with the sociocultural/historical reconstruction of the illness. It is not about the voice of patients and the subjective illness experience, either. In fact, it attempts to move away from the very subject of cancer and look at what is *outside* of this frame. The notion of space offers us an alternative based on its two properties. First, space does not propel its inhabitants to move in any linear direction, but it requires us to explore it in order to know it. Second, space may contain objects and people, and their various relationships formed with one another, which, in turn, give all kinds of meanings to space. The spatial understanding of cancer can thus decentre the scientific reasoning of biomedicine and redefines healing as located within the very experience of illness itself. The spatial perspective, I argue, offers a fuller and more complex vision of the relationship between illness, death and dying that can encompass hope, despair, bad luck and miracle, which are all part of what living with cancer means.

A holistic approach is utilised in the thesis, integrating literary, architectural and filmic material. Section One, *Stories of Cancer*, focuses on what is not being spoken in stories of cancer. It analyses scientific narratives, Dorothea Lynch's memoir *Exploding into Life* and the films *The Bucket List* and *2 Become 1*. Section Two, *The Spatial Story of Cancer*, looks at how space tells stories through an analysis of Helen Garner's novel *The Spare Room* and the network of cancer support centres known as *Maggie's Center*. Section Three, *Hope and Miracles* examines the experience of hope among family members and the holistic practice of Chinese medicine.

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Note on Chinese Romanisation

All Chinese names and terms in the main body of this thesis are Romanised according to the Hanyu Pinyin system used in the People's Republic of China. Hong Kong Cantonese names and local phrases are rendered according to the new Longman advanced Chinese dictionary. Exceptions are made in figures who are better known to readers by their names Romanised in other systems or English names.

When I mention the names of Chinese literary works, films and terms in the main text of this thesis, I provide their English translations and the pinyin Romanisation in brackets in the main text, and I provide their original Chinese names in the accompanying footnotes. I include the original Chinese characters in the main text of Chapter Seven, next to the English translations, due to the need to discuss the Chinese characters in that chapter.

For the quotation of all Chinese references, I provide their English translations in the main text and their original Chinese characters in the footnote.

For the names of Chinese authors and names of the article/book in Bibliography, I provide the Chinese Pinyin and the Chinese characters in brackets.

All translations from Chinese into English (including quotations and book and film titles) are mine unless otherwise specified. Exceptions occur in Chinese-language films appear in Conclusion, which are addressed in their standard export English titles.

Introduction

To some, illness is a private matter. For example, some people would still call cancer the “Big C” and some people would prefer not to share it with their family members and close circle of friends. To others, however, their illness stories are told in public and many of them are published. Covering illnesses ranging from AIDS and Alzheimer’s disease to cancer, these public stories are written by celebrities, intellectuals, medical professionals, and in fact people from all walks of life. Some of these stories serve to inform other patients regarding what it is like to live with a certain illness, available treatment options or the opportunity for personal/spiritual transcendence. Mostly, however, these narratives are efforts on the part of the narrator to make sense of their suffering from the illness. They can take the form of scholarly literature, or they might be creative, visual, or textual. They can be in the form of journals, academic writing, poetry, visual art, films, and even illness narratives have proven useful in the cultural exploration of health and illness. First, these narratives contribute to the knowledge of illness that exists outside biomedical discourse and spans different disciplines such as women’s studies, English studies, sociology, anthropology, and cultural studies. Second, because any representation of disease and the body, or what it means to be healthy or ill, is naturally related to an individual’s body, (social) environment, politics, and medical science, these narratives also greatly influence and shape our lay understanding of the complex relationships among illness, the body, and social-political and scientific discourse.

Illness Narratives

A narrative structure is used to organise events into various kinds of stories. The French philosopher Paul Ricoeur was probably the first to articulate the relationship between the temporal framework and storytelling in his book *Time and*

Narrative. As he states, between narrating a story and the temporality of human experience there is a correlation "that is not merely accidental but that presents a transcultural form of necessity."¹ That is to say, by using chronology, duration and temporal order, time dwells in narrative, and since human beings appraise the passage of time through narrative, narrative dwells in time. In addition, when an individual constructs a narrative about the self, the narrative becomes a representation of one's self. Donald E. Polkinghorne observes that as storytellers, we represent ourselves by organising narrative structures in accordance with the temporal structure so that the actions of our lives and the diverse events can become a meaningful whole. As a result, narratives are useful for the examinations of the concept of self as it appears in these narrative structures.² When narrative is used in the context of illness, they can be considered as not just giving meaning to temporal events, but also allowing individuals with stories of illness to change themselves and others by telling their stories.

Illness stories have been studied extensively in many different academic disciplines not only because of the narratives' potential to reconstruct the self and identity,³ but it is also because they enhance our understanding of the illness experience. Narratives offer a context in which the illness (as a disruption) and the surrounding ongoing events can be interrelated. It then becomes a new context where all events in illness can be fit in a new (or renewed) temporal framework. The genre of illness writing actually emerged in response to the biomedical discourse that neglects

¹ Paul Ricoeur, *Time and Narrative Vol. 1*. Trans. Kathleen McLaughlin and David Pellauer (Chicago: The University of Chicago Press, 1984), pp. 52-90.

² Donald E. Polkinghorne, "Narrative and Self Concept," *Journal of Narrative and Life History* (Vol. 1, No. 2-3, 1991), p. 135.

³ This is mostly studied under literary criticism and philosophy of narrative. For example, see Paul Ricoeur's *Time and Narrative Vol 1*. Trans. Kathleen McLaughlin and David Pellauer (Chicago: The University of Chicago Press, 1984), Paul Ricoeur's *Oneself As Another*. Trans. Kathleen Blamey (Chicago, The University of Chicago Press, 1992), and Jean-François Lyotard's *The Differend: Phrases in Dispute*. Trans. Georges Van Den Abbeele, (Minneapolis: The University of Minnesota Press, 1988).

the patient's embodied experience. Arthur Frank has conducted several studies on contemporary illness narrative in his paper "The Rhetoric of Self-Change" and sets forth three conditions for an illness narrative to exist:

First, for people to consider it worthwhile to write stories of their illness, and for others to read these, illness must be *individual* [and therefore not a "mass phenomenon"]...Second, for narratives to get written, survivors have to survive for some length of time...Third, the assimilation of personal experience to the "unifying general view" of clinical medicine has progressed so far that a *reaction* to it opens a space for the particular experience of individuals.⁴

Frank argues that the political columnist Stewart Alsop's account of his own leukaemia is the first example of the genre of writing contemporary illness in which the author made his own illness public.⁵ Alsop began to write about this illness in his *Newsweek* column, and ultimately these articles had culminated to become a book entitled *Stay of Execution: A Sort of Memoir*.⁶ Frank highlights three important aspects of Alsop's articles. First, Alsop emphasises that his leukaemia is not part of any mass phenomenon, and second, Alsop is intellectually engaged in his writing between his diagnosis and death, and third, his experience is narrated against the backdrop of the unifying biomedical view of his disease.

Later, in *The Wounded Storyteller*, Frank took the suffering body and the illness experience as an organic whole and further argued that ill people are more than victims of disease or patients of medicine. He called them the "wounded storytellers" and their chief mission was to make sense of their illness and suffering. Frank catalogued the common narrative patterns found in illness narratives according to three storylines: 1) the restitution narrative (which usually has a happy ending as health is expected to be restored); 2) the chaos narrative (which is often disjointed and without sequence. Its plot imagines life never getting better and events are told as the

⁴ Arthur Frank, "The Rhetoric of Self-Change: Illness Experience as Narrative," *The Sociological Quarterly* (Vol. 34, No. 1, 1993), pp. 39-40 (emphasis original).

⁵ *Ibid.*, p. 40.

⁶ See Stewart Alsop, *Stay of Execution: A Sort of Memoir* (London: Bodley Head, 1974).

storyteller experiences life, and 3) the quest narrative (in which the patient believes that something can be gained from the illness experience, such as transcendence). Quest narratives can also be read as an alternative for being well/ill.⁷

Besides Frank's classification, other scholars later also suggested different typography of illness narratives. For example, Ian Robinson, in his analysis of life trajectories in autobiographies of people with multiple sclerosis, identifies different life trajectories in illness narratives as "stable", "progressive", and "regressive".⁸ Lars-Christer Hydén suggests a different typology of illness narrative that is not based on storylines but is based on the formal aspect of the relation between the narrator, narrative, and illness.⁹ And Mike Bury remarks that there are three levels of narrative formation in the face of illness: Contingent narratives (stories about the onset, symptom and effect of illness); Moral narratives (stories exploring and evaluating altered relationships with body, self and society), and Core narratives (stories that are about changes in self-identity).¹⁰

However, Frank's pioneering approach to illness narratives is not without its critics. Warning us of "the tyranny of the narrative", Catherine Kohler Riessman argues that there should be a diversity of styles of telling one's illness story, and at the same time, we must be wary of the pitfall of "treating all talk as narrative".¹¹ Other scholars question the "naturalness" of these personal narratives as a form of meaning making. For example, Robert Zussman remarks that while stories are produced by the

⁷ Arthur Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: The University of Chicago Press, 1995), pp. 75-136.

⁸ Ian Robinson, "Personal Narratives, Social Careers and Medical Courses: Analysing Life Trajectories in Autobiographies of People with Multiple Sclerosis," *Social Science and Medicine* (Vol. 30, No. 11, 1990), pp. 1173-1186.

⁹ Lars-Christer Hydén, "Illness and Narrative," *Sociology of Health and Illness* (Vol. 19, No. 1, 1997), p. 54.

¹⁰ Mike Bury, "Illness Narratives: Fact or Fiction?" *Sociology of Health and Illness* (Vol. 23, No. 3, 2001), pp. 263-85.

¹¹ Catherine Kohler Riessman, "A Short Story About Long Stories," *Journal of Narrative and Life History* (Vol. 7, No. 1-4, 1997), p. 157.

individual about him/herself, they are also produced within and in the interests of the “institutional orders of education, religion, criminal justice, medicine, communities, families, and much more”.¹² That is to say, sometimes there are “special occasions” in which we are “compelled” to specifically reflect in systematic and extended ways on who we are and what we are.¹³ And perhaps the most critical of Frank’s approach is Paul Atkinson. Atkinson comments that despite the fact that illness narratives have offered an important analytic perspective for the research on health and medicine, we must also be aware of the fact that narrative is just one mode of representation, among many. In Atkinson’s opinion, the scholarship on illness narrative privileges individuality, interiority and authenticity, but overlooks the fact that these stories are also linguistic performances and social phenomena that do not necessarily give us direct access to the “core being” of a particular individual. As he explains:

We sell short ourselves and the possibility of systematic social analysis if we implicitly assume that autobiographical accounts or narratives of personal experience grant us untrammelled access to a realm of hyperauthenticity.¹⁴

Nonetheless, despite these criticisms of Frank’s approach to illness narratives, illness narratives as a form of (sociological) case study have gained significance in the past thirty years and have impacted on both patients and medical professionals, especially in their understanding on chronic illness. Narratives offer a means to understand how patients with chronic illness deal with their life situations on an everyday basis. For example, Bury points out that the exploration of chronic illness narratives can illuminate the nature of disrupted experience.¹⁵ In particular, he notes that under conditions of adversity, individuals are more driven to “re-examine and re-

¹² Robert Zussman, “Autobiographical Occasions: Introduction to the Special Issue,” *Qualitative Sociology* (Vol. 23, No. 1, 2001), p. 7.

¹³ *Ibid.*, pp. 6-7.

¹⁴ Paul Atkinson, “Narrative Turn or Blind Alley?” *Qualitative Health Research* (Vol. 7, No. 3, 1997), p. 341.

¹⁵ Mike Bury, “Chronic Illness as Biographical Disruption,” *Sociology of Health and Illness* (Vol. 14, No. 2, 1982) pp. 167-82.

fashion their personal narratives in an attempt to maintain a sense of identity".¹⁶ And the study of such narratives has the potential to include a wider set of issues that connect "identity, experience, and 'late modern' cultures" in a more revealing manner. Or, using arthritis as his example, Gareth Williams argues that the chronically ill needs to engage in a "more comprehensive imaginative enterprise" known as a "narrative reconstruction".¹⁷ Psychiatrist and anthropologist Arthur Kleinman has given illness narratives a broader definition in his book *The Illness Narratives*, in which he focuses on the experience of "suffering" and writes extensively on the need for effective analysis of these narratives in order to treat patients effectively as individuals.¹⁸

Besides making sense of one's suffering in everyday life circumstances, illness narratives offer a means to study the experience and the illness world as social reality apart from the concept and definition articulated by biomedicine. For example, studying the stories of patients suffering from a rare form of cancer that is a result of a "wonder drug" their mothers used during pregnancy to prevent miscarriage, Susan E. Bell considers how the cultural discourses and social structure are connected to the narratives written by patients and their embodied experience.¹⁹ And, also writing about people living with cancer, Mathieson and Stam argue that living with cancer is actually identity-altering, or, in their own words, "biography-altering", due to the facts that cancer alters one's relationships, curtails one's sense of agency, and changes one's vision of the future.²⁰ According to the authors, illness narratives serve as an

¹⁶ Mike Bury, "Illness Narratives: Fact or Fiction?", p. 264.

¹⁷ Gareth Williams, "The Genesis of Chronic Illness: Narrative Reconstruction," *Sociology of Health and Illness* (Vol. 6, No. 2, 1984) pp. 175-200.

¹⁸ Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (US: Basic Books, 1988).

¹⁹ Susan E. Bell, "Narratives and Lives: Women's Health Politics and the Diagnosis of Cancer for DES Daughters," *Narrative Inquiry* (Vol. 9, No. 2, 1999), pp. 1-43.

²⁰ Cynthia M. Mathieson and Hendaikns J. Stam, "Renegotiating Identity: Cancer Narratives," *Sociology of Health and Illness* (Vol. 17, No. 3, 1995), pp. 283-306.

important knowledge form when the notion of identity is situated at the core of one's daily life. Finally, illness narratives serve as a channel for communication between patients and physicians. For example, Rita Charon writes that knowledge otherwise unobtainable can emerge when the physician can "acknowledge, absorb, interpret, and act on the stories and plights of others. That is, to think of the patients narratively".²¹ Focusing on storytelling as a central activity, Clark and Mishler argue that the patient's attempts to tell a story shed light on the exercise of authority in clinical encounters.²²

We must also note that besides making sense of one's suffering, illness narratives are also therapeutic for the narrator – as they tell and retell their stories, they can unravel the meaning of the illness experience and begin to adjust to the person they have become. As such, illness narratives should also include creative writing because the very act of writing and the process of creating something from scratch have a certain healing effect on patients. Gillie Bolton explains the therapeutic effect of creative writing: "Therapeutic writing asks the writer to trust their body, through their writing hand, not only to tell them vital things about themselves, but also to offer routes to connecting up and making whole. Therapeutic writing is an act of faith in the self".²³ Besides the use of language, images are frequently used to enable us to understand other people's illness and suffering. Indeed, the study of illness narratives can go beyond oral and textual accounts. Again, Susan E. Bell has studied visual narratives of cancer patients and examined how the

²¹ Rita Charon, "Narrative Medicine: A Model For Empathy, Reflection, Profession and Trust," *The Journal of the American Medical Association* (Vol. 286, No. 15, 2001), p. 1897.

²² Jack A. Clark and Elliot G. Mishler, "Attending to Patient's Stories: Reframing the Clinical Task," *Sociology of Health and Illness* (Vol. 14, No. 3, 1992), pp. 344-372.

²³ Gillie Bolton, "Every Poem Breaks a Silence that had to be Overcome: The Power of Poetry Writing," *Feminist Review* (No. 62, Contemporary Women Poets, Summer, 1999), p. 20.

visual elements can incorporate with the textual element in an illness narrative.²⁴ And Sander Gilman remarks that images in the form of visual representation serve to bridge the gap between representation of illness and cultural fantasies about illness. His examination of images of mental illness in relation to the writing of medical history further links illness with culture as he argues that the images “control” a double anxiety – one that is elicited from a general feeling of mental illness by the society, and another serves to “reduce parallel anxiety about the multiple meanings of the images themselves to a controlled single interpretation.”²⁵

However, there are also limitations to what narratives can tell about an illness experience, and in particular, the cancer experience. Illness narratives help to integrate the science-driven biomedical discourse and the experience of illness and allow for an empathic reading. However, narratives generally rely on a temporal structure in which each event is arranged in a linear sequence, and that acts to limit the way an illness experience is understood, especially for a diseases such as cancer. Narratives, or any stories at all, are structured with a beginning, middle, and an end. The familiar stations of symptoms, diagnosis, treatment and/or its side effects, and a cure or recovery for some or the end of life for those less fortunate, seem to coincide nicely with the standard trajectories of most illnesses. Yet, when it comes to cancer the same trajectory does not seem to apply. For instance, most cancer patients do not intuitively know that a tumour has started to grow in their bodies until something more serious (or abnormal) is felt or observed. Cancer can also start in places where it will not cause any symptoms until it gets quite large, whereas at other times it will produce such generalised symptoms (such as fatigue and weight loss) that by the time

²⁴ Susan E. Bell, “Photo Image: Jo Spence’s Narratives of Living with Illness,” *Health (London)* (Vol. 6, No. 1, 2002) pp. 5-30.

²⁵ Sander Gilman, *Health and Illness: Images of Difference* (London: Reaktion Books Ltd., 1995) p, 18 and p. 33.

the patient suspects it could be cancer, she may have missed the “better chance for a cure”.²⁶ Another point, with which most cancer patients are likely to agree, is that cancer suffering comes not from the tumour itself, but largely from the side effects of the treatment. Both of these examples illustrate that when it comes to cancer, the temporal structure of the typical illness narrative does not accurately portray the realities of the disease.

Furthermore, illness narratives cannot effectively encompass the diversity and richness of a cancer patient’s illness experience. No matter how one tries to capture the state of cancer and no matter what choice of tense one uses to describe one’s relationship with cancer, it becomes a reminder of what cannot be fully known about the disease. Present tense seems too pessimistic, particularly when the tumour has been surgically removed, whereas past tense appears to deny the possibility of relapse. Using the future tense appears to capture some truth about the nature of the disease, given that we do live longer and, as such, our DNA is more susceptible to mutation in the long run,²⁷ but it sounds too fatalistic. Using the notion of time to understand a disease is not enough. Perhaps more importantly, because all narratives must depend on a sense of temporality, the chronological sequencing of events limits the frame of a cancer patient’s story in such a way that we become mere spectators as the events unfold before us. In other words, conventional illness narratives actually assume the starting point of the “here” and “now” as one writes/reads.

Drawing on a range of written and filmic texts, this thesis is an attempt to free cancer from the aforementioned temporal plot and explore other possibilities of

²⁶ It is believed that the earlier a tumour is detected, the better the chance that a cure will be found. See <http://www.cancer.org/Cancer/CancerBasics/signs-and-symptoms-of-cancer>. Last accessed 20 November 2010.

²⁷ In 2010, Australia’s Cancer Council stated that one in two Australians would be diagnosed with cancer by the age of 85. See Cancer Council Australia, “Facts and Figures” (<http://www.cancer.org.au/aboutcancer/FactsFigures.htm>). Last accessed 20 November 2010.

representation. Although this is a cultural study of cancer, it is not a sociocultural/historical reconstruction of the illness. Neither is it about patients' voices and their subjective illness experiences. This thesis moves away from the very subject of cancer to discover what is outside the temporal frame. To achieve a de-centred (Western) perspective of linearity and its logic of causality in relation to the disease, I propose a "spatialised" story of cancer that provides further insight into the comprehensive cancer experience. Hence, I propose a 'spatialised' story of cancer that can provide further insight into the more comprehensive cancer experience. First and foremost, the "space" within the "spatialised" story is defined as the bio-psycho-social spaces of cancer that are more than just physical, natural, and functional. It is my aim to adopt a material-ontological approach to cancer that is anti-perspectival. I hope to complexify cancer and its stories by exploring its multiple spatialities and temporalities, in which space is temporalised and time spatialised. With this approach in mind, this thesis sets out to not so much to challenge the conventional stories of cancer as to move cancer away from a temporal storytelling perspective, in which each event must be placed on a timeline in relation to other cause-and-effect relationships. It is not just a critique of the temporal approaches to telling or writing a cancer narrative, it is also an expansion, to unlock the temporal focus by opening up spatio-temporal perspectives. This attempt to achieve a "wholeness" of perspective will include the stories of victories and failures of surviving and succumbing to cancer; discussions of what is being said and what is being silenced or hidden; accounts of the visible and the invisible in its representation; exploration of what can and cannot be represented; and the Other(ed) elusive states that contribute to the cancer reality.

The Historical Understanding of Cancer as a Disease of Western Decadence

Since this thesis is partly built upon the argument that our concept of time and its linear progression is inadequate in describing and understanding the cancer experience, the aim of this section is to first establish a link between cancer as a disease and cancer as a cultural imagination. By making a historical connection between cancer and the notion of decadence (that characterised the modern capitalist society), and directing our attention to the similarity between the two, I hope it can offer a better understanding of why we tend to associate the disease as a “punishment” for something we have done in the past, “the death knell”, and more importantly, a result of societal ills. Cancer occurs when a normal cell is influenced to change its genetic code in a way that causes it to keep reproducing itself until it becomes an abnormal colony of tissues. Given its nature, cancer is typically imagined as a reflection of the illness of Western society. Like cancerous cells, Western society is characterised by its endless progress and an uneven accumulation of wealth that is further fuelled by an insatiable desire for economic growth that began during the Industrial Revolution. The history of cancer, or to be more precise the history of our understanding of cancer, is therefore tied to the evolution and development of Western culture; so much so that it is only in recent decades that Asian countries have stopped exclusively associating cancer with the West especially after it is evident that lifestyle and diet are two of the major risks.²⁸ Indeed, critiques of modern capitalism, which was often associated with over-accumulation and over-production, have sometimes used cancer as a metaphor,²⁹ and perhaps it can be traced back to the rise

²⁸ For example, see “Asia’s Western Habits May Lead to Cancer Surge,” *Associated Press*, 30 May 2007 (http://www.usatoday.com/news/health/2007-05-30-singapore-cancer_N.htm) or Roger Segelken’s “China Study II: Switch to Western Diet May Bring Western-type Diseases,” *Cornell Chronicle*, 28 June 2001 (http://www.news.cornell.edu/chronicle/01/6.28.01/china_study_ii.html).

²⁹ For literatures in which cancer has been used as a metaphor for capitalism, see David C. Korten’s *The Post-Corporate World: Life After Capitalism* (California: Berrett-Koehler Publishers, Inc., 1999), or John McMurtry’s *The Cancer Stage of Capitalism* (London: Pluto Press, 1999).

of modernity after the Enlightenment and Industrial Revolution. According to Calinescu's *Five Faces of Modernity*, progress, modernity, and decadence are conceptualised in the following way: "[...] progress and decadence imply each other so intimately that, if we were to generalise, we would reach the paradoxical conclusion that progress *is* decadence and, conversely, decadence *is* progress."³⁰ Calinescu stresses the fact that decadence is not a state, but a direction that is associated with decline, twilight, autumn, senescence, and exhaustion.³¹ Subsequently, Nietzsche further develops the idea of decadence by noting its 'deceptive' nature, which Calinescu reiterates as "that of the liar who deceives by imitating truth and by making his lies even more credible than truth itself". Calinescu concludes that "decadence is dangerous because it always disguises itself as its opposite".³²

The concept of decadence organises time horizontally and interprets it as unidirectional, such that the notion of progress (as well as decline) becomes self-destructive. Our own sense of time constellation becomes the irreversible succession of events in which the present event is the realisation of the events that precede it, such that everything we do ultimately foreshadows the future. The only difference between this and our day-to-day understanding of the linearity of time is that decadence heightens our awareness of the sense that our demise is caused by our own actions. Our ends are given a time frame and time can only lead to (self) destruction.³³ Similarly, cancer is understood as a disease of 'decadent' growth that imitates and eventually, irreversibly destroys life. Laden with Christian

³⁰ Matei Calinescu. *Five Faces of Modernity: Modernism, Avant-Garde, Decadence, Kitsch, Postmodernism*. (Durham: Duke University Press, 1987), p. 155 (italics original).

³¹ *Ibid.*

³² *Ibid.*, p.180.

³³ Decadence is associated with Christian end times: "The consciousness of decadence brings about restlessness and a need for self-examination, for agonising commitments and momentous renunciations. Christian apocalypticism, even when it does not manifest itself overly, results in a dramatically increased time awareness" (*Ibid.*, p.154).

Apocalypticism and a consciousness of the end of time, these thoughts encourage the need to rigorously scrutinise the self in an effort to avoid cancer. Thus, it is not unusual to discover that patients secretly believe that their tumour is the result of their personality – punishment for a grudge held too long, a desire that was never moderated, or pent-up anger that was never properly released.³⁴ These invisible excesses are perceived to be the ‘cause’ of the cancer, such that their very personality becomes a ‘risk’. Under such constant scrutiny, medicine becomes the only way to purify our lives of waste and harmful substances.

Within this evolutionary context, cancer is not just some error on the part of the genome, but a condition linked to a vast array of causal effects that cannot stand apart from time. In other words, it is a causal network that weaves past and present together in a more-than-linear manner. Cancer, with its one-sided growth and one-way progression, naturally signifies the approaching end of one’s time. It simultaneously appears to be within and beyond an individual’s control. Cancer stems from the growth of an individual’s own cells, but no one can ever completely control her environment. As such, cancer means only one thing: that we are aware of our “end” but unable to see through its disguise of being caused by time. Not only can we not reconstruct a past for cancer, we cannot even decide at what point on the timeline its past began. For example, cancer patients often feel the need to continue with their lives and leave cancer in the ‘past’ based on the belief that being tumour-free means that normal life will resume. People conceive of being ‘cancer-free’ as meaning that the cancer cells are no longer *there* in the body, but when were they

³⁴ Even though it is still scientifically inconclusive as to whether there is a direct connection between personality traits and cancer, some patients do tend to attribute their disease to their personality. “Cancer-prone personality” often refers to people who have a tendency not to express anger, to suppress their emotions and be compliant. See Neroli Duffy’s *A Journey Through Cancer: A Woman Doctor’s Personal Experience with Breast Cancer* (Nebraska: iUniverse, Inc, 2004), pp. 118-9. Or, see “Is There a Cancer-Prone Personality?” in *Cancer Awakens*, a cancer coaching website for cancer survivors (<http://www.cancerawakens.com/blog/2011/05/is-there-a-cancer-prone-personality-part-2/>) (last accessed 29 July 2012).

there in the first place? How do we describe the difference between before and after the DNA is damaged? To illustrate this point further, consider tobacco smoking and its relation to lung cancer. Even if the relation between the two is causal, it is still legitimate to ask at what point smoking causes the normal cells in the lungs to become cancerous. Obviously, we cannot pinpoint the first cell change, or the tenth, or even the hundredth.³⁵ Therefore, for a smoker as well as a cancer patient, the notion of time cannot explain the tumour's progression in a mechanistic, deterministic manner.

Restriction of Historicisation

One particularly undesirable consequence of understanding cancer from within a temporal frame is compulsive historicisation. By compulsive, I mean that cancer is often forced into an association with the typical storytelling mode, which is characterised by a beginning, middle, and end. Our way of understanding the disease in relation to time and the ways in which we use language to describe and situate cancer can only result in misrecognition. To recognise something, we must already have experienced or encountered it. However, we misrecognise cancer not only because we have never encountered it in any form or shape, but also because the shape is always distorted by the linear flow of time. Whatever cancer is, we already know that its narration cannot include a definitive beginning, and because it also does not have a past of its own that can be pinpointed on a timeline, it does not really belong to any part of history. Thus, it is a small wonder that any "history of cancer" must be associated with other events that have a more clearly defined and developed temporal sequence, such as an individual's life story, societal progress, scientific

³⁵ This is similar to the Sorites paradox, a problem originated by Eubulides of Miletus in the fourth century BC: If a single grain of sand is removed from a heap, the heap remains a heap, as it does after the removal of the next grain. Eubulides asked, when does it become a non-heap? Similarly, we ask at what point does an accumulation of mutated cells become a tumour, and at what point can we call it cancer?

discoveries and technological inventions, or even the history of a geographical location. The danger is that we are often led to mistake these attached events as either the *cause* or the *cure* of the disease.

This kind of compulsive historicisation presents a problem for the narrator as well. “Having cancer” is not necessarily characterised by a process of physical deterioration over time in which the disease slowly progresses forward. Neither is it about fighting illness with the help of biomedicine to restore a previous state of health, because cancer is not necessarily reversible in that its course cannot be directed backward. Without a definite direction indicating where cancer is heading within the timeframe, we are left with the general past, present and future, which all lie on the same plane under the microscopic lens of science. As a result, to narrate a cancer story and make it communicative to the reader, the narrator must locate cancer at a (false) point on the timeline as indicated by a medical diagnosis, from which a plot can then be developed. However, even the best of this type of narration cannot escape mixing the story of cancer with the story of biomedicine/science while failing to capture the elusiveness of the disease. For example, in 2011, Siddhartha Mukherjee, an oncologist and professor of medicine at Columbia University, won the Pulitzer Prize for his biography of cancer. According to Mukherjee, the idea of writing *The Emperor of All Maladies: A Biography of Cancer* came to him in 2004 when one of his terminally ill patients inquired about “the story” of cancer. The book is a memoir of his cancer patients set against the backdrop of the disease’s history. In an interview, Mukherjee explained the purpose of his book in the following way:

[My patients] were looking for a much deeper story, not their own particular medical history, but the larger context – what the origins of the diseases were, and what would happen next. What the future was [...] It’s a question I find

particularly haunting. It seems to me as a scientist that we can only understand the future by understanding the past.³⁶

In another interview, the author described writing the book as being similar to “writing a jigsaw puzzle” because the pieces were, and still are, constantly moving and changing. He also found it challenging to shift from being a doctor facing his dying patients to being a historian.³⁷

Although Mukherjee’s book is probably one of the first that allows cancer to take on its own characteristics and personality as the subject of a biography, the framing of something that is still moving and changing still requires that cancer be subjected to a unidirectional temporal frame juxtaposed by the history of medicine and governed by the rationality and logic of (the history of) science. In other words, Mukherjee presents the biography of cancer narrated from within the temporal frame, in which each event has its rightful place in time, whereas everything that does not fit into this compulsive historicisation will never be known because we can only see what is being framed to be observed from a fixed order. Similarly, when patients try to narrate their illnesses, the narrative act can only be a form of compulsive historicisation, as sociologist Arthur Frank confirms in *The Wounded Storyteller*: “The illness story is wrecked because its present is not what the past was supposed to lead up to, and the future is scarcely thinkable.”³⁸ The questions most pertinent to the cancer experience such as: Why me? and What is happening? are impossible to answer unless patients’ cancer stories are juxtaposed with their life stories to create linear plots. This merely gives rise to shame, guilt, and despair, however, because they must look back at their past to explain the present.

³⁶ <http://www.guardian.co.uk/books/2011/dec/01/biography-cancer-guardian-first-book-award> (Last accessed 03 Dec 2011).

³⁷ Decca Aikenhead, “Siddhartha Mukherjee: ‘A Positive Attitude Does Not Cure Cancer, Any More Than a Negative One Causes it.’” *The Guardian* (4 Dec 2011).

³⁸ Arthur Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago and London: The University of Chicago Press, 1995), p.55.

One thing we can do is contemplate the possibility of removing, or at least destabilising, the temporal frame, which has been traditionally used to understand the trajectory of a disease. In *Teratologies: A Cultural Study of Cancer*, cultural studies scholar Jackie Stacey notes that although medical knowledge genres are organised around temporal trajectories (diagnosis, treatment, and prognosis), we cannot accurately describe cancer in any tense, such that the disrupted temporal sequence caused by cancer must be reimagined and rescripted.³⁹ It is with this context and background in mind that I consider the possibility of telling the story of cancer in a spatial way.

Limitations of Existing Studies

There has been little academic discussion on how to tell the story of cancer in reference to space. Most research and studies concerning the use of space and its effect on illness experiences are found in the fields of medical sociology and medical geography and typically focus on the healing quality of places, geographies and landscapes. For example, medical geographers have, in recent decades, researched (mostly) Western therapeutic landscapes to explore new ways of thinking about health, place, and geography.⁴⁰ Such studies expand the concept of health and illness from the biomedical model of causal agents to include the complex interactions among physical, mental, emotional, spiritual, environmental, and societal factors.⁴¹ In particular, Wilbert Gesler researched healing places within a Western context, including natural healing environments such as Bath in England, Lourdes in France and Epidauros in Greece. Although the aforementioned locations are successful

³⁹ Jackie Stacey, *Teratologies: A Cultural Study of Cancer* (Routledge: 1997), p. 5.

⁴⁰ See Robin A. Kearns and Wilbert M. Gesler (eds.) *Putting Health into Place: Landscape, Identity, and Well-Being*; Wilbert Gesler's *Healing Places*, and Allison Williams (ed.) *Therapeutic Landscapes: The Dynamic between Place and Wellness*.

⁴¹ Allison Williams, "Changing Geographies of Care," cited in Glover and Parry, p. 98.

examples for his argument that “place matters to health”,⁴² Gesler is also aware of their contested nature, which is highly dependent on each individual’s experiences and feelings. The four healing environments that he discusses in his book, *Healing Places*, have their own unique geographic and historical contexts, which are inevitably culturally specific. To a certain extent, the study of “therapeutic landscapes” must first appeal to the metaphoric values inherent in the objects (e.g., Western culture deems water the origin of life and mountains a symbol of serenity). Even then, landscapes are ultimately subject to each individual’s own readings and interpretations. In other words, there can be an infinite number of places that are considered “healing”, as long as the inherent meanings make sense to the person and can, in turn, lend the place a healing quality.

Another problem with merely focusing on specific places with healing qualities is that these so-called “healing places” effectively render both the patient and the disease placeless. When we go to these places with the purpose of “getting away” from what is troubling us – be it stressors at home or at work or to temporarily “forget” about the everyday life that is part of the illness experience (this is especially the case for people with chronic illness and cancer) – we are consciously attempting to leave the disease behind. In other words, to feel “healed” in these places, visitors should not be reminded of what they have left behind. This is particularly noticeable with cancer. Most people find that healing only truly begins when they are at home with their loved ones in familiar environments.⁴³ Not only is returning to Mother Nature, in a very broad sense, like returning home, but also the search for places that heal is a fundamental manifestation of the desire to go back to the period in time when life was undisrupted by disease. However, identifying a place as “healing”

⁴² Wilbert M. Gesler, *Healing Places* (Maryland: Rowman and Littlefield Publishers, Inc., 2003), p. 18.

⁴³ Yi-fu Tuan, *Space and Place: The Perspective of Experience* (Minneapolis: University of Minnesota, 1977), p. 148.

does not mean that the act of healing takes place there. "Healing" in this case is narrowly defined as the absence of disease, achieved by ridding a place of any symbols of illness and adding signs of life, such as fresh flowers, new sheets, and natural sunlight. To heal from cancer, patients believe they must look forward to a time or place where cancer is not present. Such measures are also not exclusively for the patients' wellbeing. The feelings of uncertainty, anxiety, and intensified awareness of mortality affect patients and their loved ones, such that hiding and suppressing them, sometimes at patients' expense, is necessary for family members and close friends to move on with life as it existed before the cancer "episode".⁴⁴ As such, home, a typical primary healing place for most people, is paradoxically where cancer and the patient are made placeless and, in some sense, invisible. Moreover, home is the first place to house the anticipation of a loved one's death and the poignant realisation that one can never share another person's weakness, much less his fear and pain, despite being bound by love. However, while there is abundant literature on cancer patients' family members' perspectives on cancer, loss, grief, and bereavement,⁴⁵ how they survive a loved one's cancer is rarely mentioned. When cancer is foisted, unbidden, on family members and loved ones, it calls for an entirely different story of cancer, but existing studies have rarely analysed how these stories of (other people's) cancer are situated within the larger perspective.

Perhaps an even more unsatisfying aspect of the existing studies on healing places stems from the fact that once such places have been rendered "spiritually purifying" and "psychologically uplifting", there are no other places where we can

⁴⁴ Heather McKenzie and Mira Crouch, "Discordant Feelings in the Lifeworld of Cancer Survivors," *Health (London)* (Vol. 8, No. 2, 2004) 144.

⁴⁵ For example, the study conducted by Isabelle Dumont, et al. entitled "End-of-life Care and the Grieving Process: Family Caregivers Who Have Experienced the Loss of a Terminal-phase Cancer Patient" explores family members' coping styles and how they deal with anticipatory grief. In addition, Priscilla M. Koop and Vicki R. Strang's "The Bereavement Experience Following Home-based Family Caregiving for Persons with Advanced Cancer" is a qualitative study on how home-based caregiving affects the bereavement of family members.

live with the in-between, ambiguous stages of our lives. Once these places have been conceptually removed from the intrusion of science and technology and, consequently, from life's necessary routines and failures (such as dying and death), what remains? What happens to those in the terminal stage of an illness, or those trapped in a constant state of worry about a recurrence that can never be "healed"? Hospices give us a clue. A hospice is a place where we prepare not only for death, but also for the suffering at the end-stage of life. Hospice patients wish to exit life with dignity and comfort with the knowledge that pain will not wrench their last moments of life away from them. Therefore, death with dignity is not just an option; it becomes a necessity. French historian Philippe Ariès sardonically remarks in *The Hour of Our Death* that:

A small elite of anthropologists, psychologists, and sociologists [...] propose to reconcile death with happiness. Death must simply become the discreet but dignified exit of a peaceful person from a helpful society that is not torn, not even overly upset by the idea of a biological transition without significance, without pain or suffering, and ultimately without fear.⁴⁶

Unfortunately, Ariès offers the above passage towards the end of his book without suggesting alternatives to this space of dying and death.

Time and Space and Their Inter-relation

Looking at cancer and its stories from a spatial perspective is an attempt to explore cancer as a changing and complex object. Throughout this thesis, I aim to decentre cancer from the patient's point of view to look at what else is there. In particular, I am interested in the varied and various spaces, times, and objects that contain and surround cancer such as rooms, buildings, the environment, and even fictional spaces. By turning and moving around and within these spaces, I hope that we can find out what *else* we can learn about cancer from different cultural texts,

⁴⁶ Philippe Ariès, *The Hour of Our Death*. Trans. Helen Weaver (New York: A.A. Knopf, 1981), p. 614.

apart from the illness narratives that we are familiar with. This surrounding space that is around the object called cancer is what I refer to as the “space of cancer”.

But first, further defining the “space” within the “space of cancer” is necessary. The concepts of “Space” and “Time” often go hand in hand. The concepts of space and time have traditionally been understood as objective, Newtonian, and absolute. In this understanding, space is three dimensional and time belongs to a separate dimension. However, physics in the twentieth-century proved that time is not a separate dimension after all; rather, it should be conceived as irreversible and as constitutive of all physical and social entities according to the expansion of the universe after the historical event of the “big bang”.⁴⁷ However, space and time are central to social theory as well as scientific theory. For example, geographers Jon May and Nigel Thrift, in their book *Timespace*, outline the multiple and dynamic forms of time, and set out four interrelated, spatially constituted domains of social practice that enable these forms to be constructed. These domains comprise: i) our sense of time as shaped by the rhythms set according to the inter-relations of Time and Space in the natural universe, such as the diurnal cycle, and the rhythm of seasons ; ii) our sense of time as shaped by various systems of social disciplines; such as work time versus family time; iii) our sense of time that emerges from instruments and device, such as the VCR; and finally iv) our sense of time that emerges in relation to various texts that one can derive social meaning from and form new conceptualisation of time itself.⁴⁸ What this means is that while our lives are inevitably shaped by these social constructions of time, our understanding of time has become dependent on our understanding of space, where social activities take place,

⁴⁷ John Urry, “The Sociology of Space and Place,” *Blackwell Companion to Sociology*, ed. Judith R. Blau (Malden, Mass: Blackwell, 2001), p. 10

⁴⁸ Jon May and Nigel Thrift, “Introduction,” *Timespace: Geographies of Temporality*, ed. Jon May and Nigel Thrift (London and New York: Routledge, 2001), p. 4.

and vice versa. On a larger scale, the inter-dependency of time and space implies that changes in the nature of one could have impact upon changes in the nature and experience of the other. A vivid example is the “time-space compression” identified by David Harvey as the root of the postmodern condition. According to Harvey, “innovations [such as telegraph, the automobile, radio, etc] dedicated to the removal of spatial barriers...have been of immense significance in the history of capitalism, turning that history into a very geographical affair”.⁴⁹ In fact, contrary to the expansion of the universe (so that time can be considered as progressing forward and space is given some kind of “history), Harvey’s “time-space compression” describes the world as collapsing inward upon us as a result of the speed-up in the pace of life and the overcoming spatial barriers.⁵⁰ In other words, speed erases duration and distance that used to give meanings and measurements to space.

The evolution of the conception of time and space also plays an important role in the rise of a longing for a sense of continuity in a “compressed”, fragmented world characterising the postmodern condition. One of human’s defence mechanisms appears to be nostalgia, as Linda Hutcheon puts it:

Time, unlike space, cannot be returned to [...]; time is irreversible. And nostalgia becomes the reaction to that sad fact.⁵¹

That is to say, nostalgia is not simply a desire to return home, it is to return to an irrecoverable time, like one’s youth. It is more than travelling through space to arrive at a destination; rather, it is a longing for a certain (imagined) space that

⁴⁹ David Harvey, *The Condition of Postmodernity: An Enquiry into the Origins of Cultural Change* (Wiley: 1989) p. 232.

⁵⁰ *Ibid.*, p. 240,

⁵¹ Linda Hutcheon, Linda. “Irony, Nostalgia, and the Postmodern,” *Methods for the Study of Literature as Cultural Memory*, (2000, no pagination).

<http://www.library.utoronto.ca/utel/criticism/hutchinp.html>.

has already been erased by time. Here, the complex space-time relation is articulated by Svetlana Boym when she explains what nostalgia really is:

Nostalgia appears to be a longing for a place but is actually a yearning for a different time—the time of our childhood, the slower rhythms of our dreams. In a broader sense, nostalgia is a rebellion against the modern idea of time, the time of history and progress. The nostalgic desires to obliterate history and turn it into private or collective mythology, to revisit time as space, refusing to surrender to the irreversibility of time that plagues the human condition.⁵²

According to her, this place that nostalgia longs to return to is partly constituted by time, albeit it is a lost one. As such, in nostalgia, time is spatialised (as in restorative nostalgia in which emblems and rituals of home and homeland are reconstructed), and space is temporalised (as in reflective nostalgia where shattered fragments of memory are cherished).⁵³

This is the backdrop against which the spatial story of cancer is conceived. When it comes to health and illness, is time considered “irreversible”? Can the experience of illness be yet another spatially constituted domain that helps construct a new sense of time? Can we situate the stories of cancer within which time can be spatialised and space can be temporalised as a response? What kind of space can the space of cancer be?

The Function of the “Space of Cancer”

Perhaps it is always easier to understand illness in terms of time. For example, some of us tend to believe that most diseases throughout the course of our lives are just “bumps on the road” (i.e. time is endless); and some of us believe that nipping the disease in the bud by going to the doctor as soon as we feel something is wrong is the best way to prevent a disease from becoming life-threatening (i.e. a disease is always progressing forward with time). Not only are these beliefs

⁵²Svetlana Boym, *The Future of Nostalgia* (New York: Basic Books, 2001) p. xv.

⁵³*Ibid.*, p. 40.

implying that time is irreversible, but the notion of time is also used to imagine how the disease “grows” inside the body as time comes and goes. But how, or to what extent is our understanding of disease and illness shaped by the notion of space? A hospital is probably what first comes to the mind. It is a place one goes to for the treatment of a disease, and it is where health is expected to resume in the care of medical professionals. And then there is nature. As I have mentioned earlier, we may say that a certain natural space is ideal for healing from an illness. Nature, in this sense, is a space that is related to holistic healing from the disease. However, whether it is healing just the body in the hospital, or both the mind and the body in one’s favourite natural space, when used in relation to health and illness, space is usually referred to healing – to get rid of the disease or what is troubling the body (and mind). One may even venture to say that when we talk about space in relation to illness, it mainly serves to distance the patients from the “here” and “now” of the disease by either physically or spiritually transporting them away from the illness experience, and this is what also defines the journey of healing.

However, within stories of cancer, does space have any specific role at all besides healing? Robert Pope’s paintings offer the viewers insight into the patient’s experience of cancer (as well as what cancer looks like) through the visual depiction of his hospital room in Princess Margaret Hospital, a cancer hospital in Toronto. The scenes both inside and outside of his room play an important part in giving meaning to what cancer is, and the patient’s experience with the disease:

Like many of his paintings, the scene in the room and mountain in the distance are a metaphor for his illness. In the room we see the relationship of the person weakened by illness but comforted by a concerned caregiver, while the distant mountain representing the looming cancer lurks in the distance.⁵⁴

⁵⁴ Jock Murray, “Robert Pope: Images of Illness,” p. 112 (<http://robertpopefoundation.com/wp-content/uploads/2011/04/Pope-pages-v2-106-130.pdf>).

To the patient, the room and its surrounding become meaningful because they are where his cancer is mostly experienced. They become the setting and *mise en scène* from which his story can be told. However, these paintings do not offer us any further insight as to how space itself figures in the temporal story of cancer. To put it differently, the spatial experience of cancer in the hospital room fails to join with the temporal experience of the illness to form a complex space-time relation, nor does it offer a different storyness to cancer that can free it from the conventional illness trajectory that I mentioned earlier. So perhaps the “space” of cancer should go beyond the convenient imagination of a hospital room, and what is outside its window.

In *For Space*, geographer Doreen Massey offers us an alternative approach to space. First, according to her, space is the product of interactions and interrelations; second, the existence of multiplicity is possible in space (Here, Massey uses the “story of the world” as an example and claims that history cannot be told as the story of the “West” alone), therefore, an acknowledgement of the heterogeneity of storyness is also an acknowledgement of the multiplicity of spatiality. Third, space is always under construction, it is never finished and never closed. In other words, it is what Massey later calls a “simultaneity of stories-so-far”, meaning that space offers the coeval existence of multiplicity. For example, right now people in Beijing are sleeping, right now somebody is walking her dog in Sydney, right now some patients are certified dead at a hospital.⁵⁵ There can be many storylines going on at the same time in different spaces. In this imagination, space is made up of continuous movements, or trajectories, and these movements are not just spatial, but also temporal. It is precisely because of its temporal quality within that space, space

⁵⁵ See Doreen Massey, *For Space* (London: SAGE Publications, 2005) pp. 10-11; and Doreen Massey, “Some Times of Space,” *Olafur Eliasson: The Weather Project*, ed. Susan May (Exhibition catalogue. London: Tate Publishing, 2003) pp. 107-118.

is also “irreversible”. Here, Massey uses the example of travelling from Manchester to Liverpool to explain how, contrary to what Hutcheon writes earlier, the space of a certain city is not the same as it was five minutes ago (so space is just as irreversible as time). That is to say, space has time/times in it, and that movement, encounter, and making of relationships takes time.⁵⁶ Space is never static, nor is it a passive destination; a closed system. This is how the space of cancer is constituted. It is ongoing, open, and fluid. It is not about where cancer is located, or where cancer’s story can be found. It is not where the cancer stories are told, such as from the hospital, the hospice, or a bedroom. It is, rather, a collection of trajectories that make up the space, a “simultaneity of movement”.

The story of cancer is often flattened into some kind of personal history or strive-to-survive story, while healing requires that we move away from the illness experience, with the distance traversed mapping a battle well fought. Viewing the story of cancer this way can be likened to having a bird’s eye view of a supposedly three-dimensional series of events unfolding below. To read the “flattened” panoramic account from above, one would have to re-order what one is seeing in a linear, comprehensible manner – either by looking from left to right, right to left, top to bottom, bottom to top, or in a clockwise/anticlockwise direction. Imagine looking at a panoramic view of a city from above. To make sense of what we see, we must use the cardinal directions of East, West, North and South as a guide. However, once we descend into the space below we can see, or be distracted by, everything *else* that makes up the city space, such as crowds and noises, traffic and smells, and signs and disorder. Borrowing from Massey’s analogy of travelling from Manchester to Liverpool, I propose that the process of spatialisation should be understood as walking through this imagined space, and exploring its labyrinths –

⁵⁶ Massey, “Some Times of Space,” p. 108.

which have an opaque past and an uncertain future. Not only could we then interact actively with this space of cancer, we could also be acutely aware of the simultaneity these stories imply, creating collections of trajectories that make up the space that has time/times in it.

Hence, the major difference between a biographer of and a participant in this space is explained by what de Certeau refers to as “a practitioner” in his seminal work, *The Practice of Everyday Life*:

The practitioners make use of spaces that cannot be seen; their knowledge of them is as blind as that of lovers in each other's arms. The paths that correspond in this intertwining, unrecognised poems in which each body is an element signed by many others, elude legibility.⁵⁷

By imagining ourselves as walking through the space of the unseen, unrecognised, and elusive, which, together, constitute the “thickness” of the cancer story, we exceed the roles of spectator and author because we are actually practising existing among these networks of moving, intersecting stories shaped from the “fragments of trajectories and alterations of spaces”.⁵⁸ More importantly, this is a space that can be traversed not only by cancer patients, but also by those who are affected by cancer, those who are just passing by, or those who are simply curious. Hence, unlike the kingdom of the ill, this space is not monotonous with the voice of the patient because it is also populated by others' stories.

One function of the space of cancer, apart from telling the “spatial” story of cancer, is to serve as a place for all of us to “walk” through without knowing what to expect, but still able to hope. The notion of walking implies that an individual (such as one of de Certeau's practitioners) is not necessarily deprived of mobility or movement and is thus free to search for an exit if she wishes. In this way, “walking

⁵⁷ Michel de Certeau, *The Practice of Everyday Life*, trans. Steven Rendall (Berkeley: University of California Press, 1984), p. 93.

⁵⁸ *ibid.*

through” the space of cancer also becomes a “journey of healing”. As such, the first distinctive feature of this space is the presence of cancer. We understand this space of cancer as a space of healing precisely because it is also where cancer is located and situated. This space of cancer is not necessarily a “safe place” where all “Others” are expelled. It is also not a sterilised or purified space. The notion of “healing” is not necessarily a process of getting rid of the disease or denying its presence – a distinction that is particularly important in the spatial story of cancer.

For most cancer patients, healing begins but does not really end. Surgically removing the tumour from the body does not necessarily heal the patient. Even without the tumours, cancer still haunts different aspects of patients’ lives, but these aspects do not really belong to the cancer narrative or any story of healing due to the ways in which our language defines health and illness. Because the definition of one thing is often based on its opposite meaning in our language system, health is often understood as the absence of illness in the body. Illness is defined as an awareness that something is wrong with the body, but when the body is considered healthy, we do not necessarily *feel* the presence of the sentient body.⁵⁹ In other cases, we can imagine what something is like through knowledge of its opposite without having to experience it directly, such as in the case of life and death. There are just as many concepts that cannot be understood through such binary construction, however, such as suicide, crime, faith, accidents, and miracles. Because there is no definitive opposite of “crime”, we must devise anti-crime campaigns to fight against it, which coincidentally explains why cultural critic, Jean Baudrillard, did not think that terrorism could be abolished through political measures or military force.⁶⁰

⁵⁹ Drew Leder, “A Tale of Two Bodies: The Cartesian Corpse and the Lived Body,” *The Body in Medical Thought and Practice*. Ed. Drew Leder (The Netherlands: Kluwer Academic Publishers, 1992), pp. 17-35.

⁶⁰ See Jean Baudrillard’s “Prophylaxis and Virulence,” in *The Transparency of Evil: Essays on Extreme Phenomena*, trans. James Benedict (London and New York: Verso, 1993) pp. 60-70.

Baudrillard explained that such political campaigns placed “anti-terrorism” in the realm of “being free from” or “being most unlike” terrorism, whereas in reality the two have too much in common to be opposites. Likewise, the current biomedical solution to cancer, which is in the form of anti-cancer treatment (chemo- and radiotherapy), cannot not be understood as the opposite of what cancer does to the body (cancer “ravages” and chemo- and radiotherapy “heal”). In fact, the severe side effects of these treatments are proof that our obsession with the notion of *anti-* in relation to cancer is not a viable solution to the disease.

The second major feature of the space of cancer is that it has a particular topology that makes it mutable, expandable, and fluid. Here, actor-network theory (ANT) as developed by sociologists John Law and Annemarie Mol is the most useful tool for understanding the topological features of this space. In particular, Law and Mol’s notion of “fluid spatiality” – a topological system that I will elaborate on in Chapter Five – is ideal for discussing the function of this space.⁶¹ According to Law and Mol, “fluid spatiality” means that an object obtains same shape constancy without having to depend on any particular defining feature or relationships to keep it stable. In this way, it will appear that it shifts and moves, which allows it to perform continuously but function somewhat differently each time.⁶² When applied to the space of cancer, fluid spatiality indicates that it is constantly and continuously changing. It “moves” by interacting with its practitioners and forms different relationships within networks. It also adopts different shapes that ultimately change

⁶¹ John Law, “Making a Mess with Method,” version of 19 January 2006, available at <http://www.heterogeneities.net/publications/Law2006MakingaMesswithMethod.pdf>, downloaded on 22 October 2010; and *After Method: Mess in Social Science Research*. London and New York: Routledge, 2004.

⁶² This refers to the Zimbabwe bush pump, which “looks different from one village to the next, and it works differently from one set up to the next, yet it is still the same pump in the sense that it is the ‘Zimbabwe bush pump’ that moves to so many places in rural Zimbabwe and that moves precisely because it is not an invariant shape either in network or in Euclidean space”. See John Law and Annemarie Mol, “Situating Technoscience: an Inquiry into Spatialities,” *Environment and Planning D: Society and Space* (Vol. 19, No. 5, 2001) pp. 613-5.

the way we perceive the realities of cancer because they, too, become heterogeneous and mutable.

Thesis Outline

In this study, I first and foremost examine what falls outside the traditional narrative of the cancer experience. This includes death and dying, which are part of the cancer experience but are often only implied at the end of conventional illness narratives as a form of closure. Second, I argue that having a spatial story of cancer means integrating our illness and spatial experiences, which requires that we remain open to the other voices simultaneously telling the story. These other voices include those of human storytellers and those of the objects and aspects we interact with. Finally, I look at the stories of others, specifically the ways in which hope is sustained by family members in this space and how miracles can take us beyond the boundaries erected by biomedicine and Western science.

I use a holistic approach in this thesis to integrate literary, architectural, and filmic material with the goal of composing a cross-disciplinary view of the possibility of using a spatial structure to tell the story of cancer. The key question I ask is whether a “spatialised” story of cancer will shed some light on the Other(ed) realities of cancer, which include death and dying and the other “undignified” feelings associated with the processes of hope and healing.

My thesis is composed of seven themed chapters that are organised into three different sections. I open the thesis with a chapter on the biomedical space of cancer in which I discuss the elusive nature of the disease. This is followed by Chapters on the “cultural trajectories” that commonly tell the stories of cancer: autopathography and film. In this section, I turn to the ghostly trails and traces in the former and the historical development of “cancer films” as a subgenre in the latter. Specifically, I

look at how these films turn from being educational to being a plot device to being something to “laugh about”. The next section is devoted to another two chapters on the “physical trajectories” that make up the “spatial stories of cancer”, with one being fictional and the other architectural. Finally, the two chapters in the last section “Hope and Miracle” discuss two more (imaginary) trajectories that are concerned with the “magical”. The first one emphasises the role imagination plays in the journey of healing, and lastly, the healing-suffering body as landscape offers the final set of trajectories that open up a different and alternative spatial perspective for the story of cancer.

Section One, *Stories of Cancer*, focuses paradoxically on what is *not* being spoken in stories of cancer. My primary aim in this section is to decentre perspectives, and I focus on the types of textual materials that are most readily available to the lay public’s efforts to understand cancer in Western culture, including scientific, literary, and filmic narratives. I argue that while these texts do tell us what cancer is by letting us read or see what is being written/depicted, they tell us just as much, if not more, about what is hidden/made invisible or silenced. However, they can only be perceived this way once the subjective perspective has been de-centred. More importantly, by suggesting that stories of cancer cannot be coherent, universal, or one-dimensional, perhaps we can add an extra dimension of “thickness” to these accounts – comprising the invisible, the silenced, and the negative – to arrive at a fuller story of what cancer really is.

Any discussion of cancer must sooner or later raise the question of its relation to biomedical and scientific discourses. Traditionally, medical discourse has been viewed as the most authoritative voice on the subject of cancer because it is perceived as rational, logical, and objective. In Chapter One I look at the main components of a

particular type of scientific narrative, namely, the biomedical discourse of cancer. I argue that despite biomedicine's highly specialised perspective, when attempting to define a disease like cancer, it produces divisive and heterogeneous discourses, rendering cancer a complex phenomenon that remains elusive. This highlights the elusiveness of cancer within the biomedical space. As much as scientific discourse attempts to reduce the complexities of cancer into a single, reductive theory operated by cause-and-effect rationality, questions continue to emerge and proliferate. These questions – those that elude our understanding – have profound implications on the patient's cancer experience just the same.

Chapter Two focuses on another common genre of the cancer story, specifically the personal narratives of cancer patients, and examines the alternative to a linear temporal structure when telling the story of cancer. In this chapter, I use Dorothea Lynch and Eugene Richards' photo-journal of Lynch's cancer experience entitled *Exploding into Life* to analyse how a cancer narrative embodies not only writing about one's life, but also what can be seen, what is repressed, and how what is repressed can return in different forms. I argue that by directing our attention to what is present but invisible in a representation, the "ghostliness" of the cancer experience can tell us more about the collective story of cancer. Due to the unique nature of this disease, a cancer experience cannot simply be understood as a linear sequence of events; rather, it requires its own distinctive temporal structure capable of giving rise to a unique "storyness". Hence, in this chapter, I argue that people living with cancer exist in various timearcs that differ from the linear, chronological timeline that structures most (auto)biographies. These timearcs "shift," "spiral," "slip," and even "suspend" to create a three-dimensional temporal structure in which the movement of time is more varied. As such, each piece of a timearc belongs to part of a time spiral, which ensures that one does not overlap another. This, in turn, creates a negative

space populated by the unspeakable and unrepresentable – the “ghostliness” of cancer.

In Chapter Three I analyse filmic stories of cancer as yet another cultural response to the disease and argue that the main function of these films is to express what has been suppressed and silenced by cancer patients, themselves. This is achieved through the use of ellipses (an omission that cannot be fully articulated) in their storytelling and through the extraction of humour from the mundane in storytelling. I begin this chapter by analysing the structure of cinematic cancer narratives to find out how these texts have helped shape our popular, lay understanding of the disease. By comparing “screen cancer” with epidemic cinema that successfully captures the fascination of the audience, I argue that not all “screen illnesses” are portrayed as horrifying or melodramatic. In fact, cancer films engage the audience’s emotions through different channels. I show that it is their ability to use what is not being said/portrayed, rather than the traditional cinematic use of visuals (like their epidemic counterparts), that has made cancer films one of the popular genres of cinematic illness representation. Finally, I support my argument by examining the Hollywood film *The Bucket List* (Dir. Rob Reiner, 2007) and the Hong Kong film *2 Become 1* (Dir. Wing-cheong Law, 2007).

While Section One focuses on what is *not* there, Section Two, *The Spatial Story of Cancer*, looks at how space tells stories. As previously mentioned, the space of cancer can be understood in the context of Sontag’s “kingdom of the ill” when situating and spatialising the story of cancer. This section offers two versions of such space: a spare room and a cancer support centre. The main function of this section is to identify how cancer is situated in these spaces and argue that it is only by “emplacing” cancer that a space can become healing. To heal, the presence of illness

and the unwanted, unhealthy, or negative emotions that come with it cannot be suppressed or made invisible. Healing, to a certain extent, is a spatial experience that requires active interaction (through communication) and participation (through movement) with the illness experience.

Chapter Four examines *The Spare Room*,⁶³ a fictional work by Australian author, Helen Garner (1942-). This text is an example of how space can tell a story of cancer that differs from the accounts of the narrator (Helen) and the protagonist (Nicola). Throughout the novel, Garner describes the cancer reality via the configuration of what she refers to as the “material world”. In other words, the story of cancer is depicted through the shapes, sounds, and mise-en-scene of the novel, which gives the reader more than just a description of the subjective experience. Through the personal interactions between Nicola (the patient) and Helen (the observer), the novel offers a material reality woven from their communication and interaction with the objects around them. In this chapter, I argue that not only does this work of fiction allow multifaceted realities (both material and immaterial) to emerge, but also both the spare room discussed in this chapter and *The Spare Room* house the ambiguities and elusive aspects that are part of the story of cancer.

Chapter Five examines the spatial experience of healing. It focuses on the place and space of two cancer-care centres, namely, Gilda’s Club and Maggie’s Centre, and analyses their social and spatial functions to show how they affect the cancer experiences and healing of those who use them. Gilda’s Club is a group of cancer-care centres in North America and by arguing that a place is defined by its function, I show how the Gilda’s Club is a “third place” that serves a different function from home and other medical institutions. As such, the centre as a “third

⁶³ Helen Garner, *The Spare Room* (Australia: Text Publishing, 2009).

place” is a place for the free exchange of stories and cancer experiences and it is a place constantly shaped by its users’ storytelling. Next, I analyse the spatial and architectural design of a network of cancer-care and support centres located mostly in Scotland known as Maggie’s Centre. I show how each Centre is both a space and an artefact that bears a healing quality on its own. Drawing on Bruno Latour and John Law’s actor-network theory, I argue that Maggie’s Centre allows our spatial experience to interact with the illness experience and how this, in turn, forms a multi-directional communication between space, place, and object that contributes to a space of healing. And since these Centres are also constructed in larger urban landscapes, I argue that they help us see how the exteriority and interiority of different spaces can merge and interact with each other. As an artefact, the Centre “changes” shape as it moves, adapts, expands, merges, opens, and shifts according to how one’s experience with cancer interacts with its materiality and immateriality; exteriority and interiority.

Section Three, *Hope and Miracles*, is a further contemplation of what *else* can be expected from the space of cancer. This section is concerned with the “journey of healing” as one’s effort to seek an exit from the space of cancer. I offer two suggestions for how this might be achieved: through hope (Chapter Six) and by seeking an alternative path, such as that represented by miracles (Chapter Seven). By analysing the workings of hope and the presence of miracles, this section simultaneously addresses that which eludes theories and theorisation, but which nonetheless constitutes the cancer experience. Not only do we need hope to survive, we also need to accept the fact that miracles are just like accidents – they simply happen – and should not be removed from the cancer experience just because they cannot be narrativised. As such, the space of cancer embodies more than fighting the war against cancer armed only with courageous resistance and the desire to survive.

It is also about honouring each moment that comes (without temporalising it) and recognising the ups, the downs, and the things that do not necessarily make sense.

Chapter Six is an investigation of hope and how it serves family members striving to survive the cancer of a loved one. In this chapter, I argue that imagination is not only an important ingredient for hope, but also for what others believe to be “magic” to happen. I begin this chapter with a theoretical analysis of the function of hope based on the philosophical writings of Ernst Bloch, Brian Massumi, and Alphonso Lingis. Because hope is an affective energy that keeps us moving forward, my analysis addresses how hope can help family members to survive someone else’s cancer despite having little-to-no control over the situation – a process that involves constant and continuous adjustments and negotiations between reality and what they hope for. Next, I draw on nursing and palliative care literature to demonstrate that hope is visual and closely related to imagination. Finally, I offer two examples – one novel and one film – to illustrate that imagination is not always used to create “useful” images that add to our knowledge of cancer. Sometimes imaginations can produce what I called “useless” images that can work like magic and help trick the mind into believing that things will get better, even when there is nothing left to hope for.

In Chapter Seven I argue that although alternative medicine may not be the answer to the things conventional medicine cannot do, it opens up a more complex system in which healing, much like everything else in life including accidents, failures, and luck, is aleatory, open to chance, and circumstantial. Focusing on Traditional Chinese Medicine, this chapter begins by examining the holistic nature of its practice, particularly how it understands the complex and complementary relationship between nature and the human body. This is followed by an attempt to delimit the boundaries between science and “non-science” to explain the presence of

miracles/accidents, especially within the practice of Traditional Chinese Medicine. Because what makes clinical “miracles” possible in Traditional Chinese Medicine is simply what cannot be explained by Western medical science, I argue that this can also be applied to the concept of healing, such that once it is situated in a more complex system that exceeds the boundaries of Western science and biomedicine, it no longer needs to remain pinned under the biomedical lens for speculation and examination.

Chapter One - The History of Cancer

What is cancer? If cancer is a disease, how is it transmitted?

of childhood cancer be explained? If that

such as smoking tobacco, that how can a child

cancers, commonly found in fruits and vegetables, and

radical the rise of cancer? Why does such a low

incidence of cancer exist today's society? How can we

scientific discovery to help us understand cancer?

normal cell can be transformed? As a result

and how has the study of cancer helped us understand

technology in the future? Why will

authoritative source of information on

continue to be a major focus of research in

SECTION I:

STORIES OF CANCER

It is a story of a man who

arguably a great scientist

Scientist, he is not a

advertisement, but a

popular figure

are about as diverse

cannot be understood

found in the history

cannot be more like a

a scientific goal. In other words, there will

out or omitted for the sake of simplicity. On

scholars American Mel and John Lawton



Chapter One – The Scientific Stories of Cancer

What is cancer? If cancer is a disease of old age, then how can the occurrence of childhood cancer be explained? If there are definite known cause(s) of cancer, such as smoking tobacco, then how can all of the exceptions be explained? If beta-carotene, commonly found in fruits and vegetables, is an antioxidant believed to reduce the risk of cancer, why does such knowledge not actually help reduce the incidence of cancer in today's society? How can the lay public benefit from genetic scientific discoveries, such as that of an oncogene that is responsible for converting a normal cell into a cancerous cell? As a science concerned with human health, medicine has played a crucial role in the general representation of science and technology to the public. Even with its well-vaunted scientific objectivity and authoritative voice that help illuminating the disease, at the same time, medicine continues to shroud cancer in mysteries, misunderstandings, and fear.

In this chapter, rather than reviewing what we can know about cancer from the available scientific narratives, I look at what has not been said in these narratives. Scientific narratives come in many forms, which may vary from a 30 second TV advertisement, a conversation about risk with one's doctor, a textbook, a piece in a popular magazine, and even a forum on the Internet. In addition, different narratives are aimed at different publics. However, even though we have all this information, cancer still exceeds and defies definition. Our knowledge of cancer cannot be solely found in what is "presented" in these scientific and biomedical discourses since cancer is more like a complex object simplified due to a certain type of ordering (e.g. a scientific one). In other words, there will always be *other* things that are being left out or omitted for the sake of simplicity. Or, as science and technology studies scholars Annemarie Mol and John Law argue:

“What is said, what is allowed as an element in order, always depends on what is not said, on what is displaced and marginalised – this is the general trope. But in this time-sensitive version that expelled other has not gone away because while it is absent it is still present, too.”¹

That is to say, the more complex the object of study is, the more we tend to press it into a familiar shape that excludes anomalies that do not fit. This expelled elusive and chaotic complexity is not necessarily repressed; rather, it is productive. Thus, this chapter is also about how we can make use of what is present/absent; said/unsaid; manifested and displaced to “produce” other complexities of cancer. This will also set forth a view of cancer that suggests cancer is a large and amorphous phenomenon beyond mere medical description.

I begin this chapter with the assertion that scientific knowledge is socially and culturally constructed, and that there is a limitation of our (both as lay people and as medical professionals) scientific understandings of cancer. I will provide some background about what we generally consider as the scientific/medical “facts” of cancer before we proceed to what is not being said in these “facts”. Next, I identify four components in the scientific discourse of cancer that serve as “truth-markers” as well as tools to simplify scientific theory. These components include: i) medical definitions; ii) signs and symptoms; iii) cause and effect; and iv) numbers and statistics. I show what each of them tells us about cancer, but at the same time, also what it *fails* to tell us. I argue that we must attend to a combination of what it says and what it has left out in order for us to paint a fuller, albeit incoherent, picture of the cancer reality. Such complexity is defined by Mol and Law in the following way:

¹ Annemarie Mol and John Law, “Complexities: An Introduction,” *Complexities: Social Studies of Knowledge Practices*. Ed. Annemarie Mol and John Law (Durham and London: Duke University Press, 2002), p. 13.

“There is complexity if things relate but don’t add up, if events occur but not within the processes of linear time, and if phenomena share but cannot be mapped in terms of a single set of three-dimensional coordinates.”²

Thus, by examining the ever multiplying and discordant stories of cancer that begin from, but are constantly expanding beyond, the realm of scientific and biomedical definition, we will be confronted with contradictions and anomalies that make up cancer’s complexity. Finally, I show that despite the attempt to provide a tidy reductive theory of cancer, what is left out for the sake of “scientific simplification” will inevitably create another form of complexity elsewhere. More specifically, I argue that what is effaced may emerge in other forms and locales such as political debates and struggles about cancer.

Scientific Knowledge of Cancer

When we want to know more about what cancer is, or when we look for related information and resources on the Internet, we tend to refer to websites that belong to government Health Department, well-established, non-governmental cancer research institutions such as Cancer Council Australia, the American Cancer Society, or perhaps even to medical journals. To most lay public, these websites (and institutions) are considered more “trustworthy” than websites such as Wikipedia, other commercial websites, personal web blogs and other less well-known medical websites such as medicinet.com and webmd.com.³ The information provided by the trusted websites is naturally considered more official and scientific, and therefore more authoritative. Yet, does this mean that these trusted sites are necessarily representing the kind of scientific knowledge that is telling us all there is to know about the disease? Before we begin the discussion of what is being excluded from composing the

² Annemarie Mol and John Law, “Complexities: An Introduction,” *Complexities: Social Studies of Knowledge Practices*. Ed. Annemarie Mol and John Law (Durham and London: Duke University Press, 2002) p, 1.

³ These are examples of the common results from the first page of a Google search of the word “cancer”.

scientific/biomedical narrative of cancer, it is necessary to start with a brief overview of the development of scholarly discussions of the production of scientific knowledge.

Knowledge is different from opinion, superstition, wishful thinking, and ideology. Knowledge is supposedly official and, in the case of scientific knowledge, should correspond correctly to representations of reality. However, if science has always been considered as trustworthy and effective in producing knowledge and explaining the world around us, the emergence of the philosophy of science and the studies of science and technology has served as evidence that science is socially produced, that they are part of social activities. Thomas Kuhn has perhaps been most well known for challenging the dominant discourse of science as he argued that scientific truth cannot be established solely by objective criteria. In his essay "Objectivity, Value Judgment, and Theory Choice", he stresses that science is just what scientists do, and theory choice is made according to five objective criteria, namely, accuracy, internal and external consistency, a broad scope, simplicity, and fruitfulness, to aid in the choice of one theory over another.⁴ Kuhn's account of the production of scientific knowledge enabled other scholars to think about science in very different terms. Feminist science scholar Helen Longino, in her *Science as Social Knowledge*, makes a distinction between Kuhn's criteria as "constitutive values" that enhances the likelihood of the truth of a theory, and what she calls "contextual values". In her opinion, the social and practical interests vested in the knowledge production of science now have a part in determining what count as good or acceptable scientific judgment. The social and cultural environment is where science is "done", and to talk about the content of science is to be constantly aware of

⁴ Thomas Kuhn, "Objectivity, Value Judgment, and Theory Choice," in *The Essential Tension: Selected Studies in Scientific Tradition and Change* (Chicago: The University of Chicago Press, 1977), pp. 320-339.

its contextual values – to question its integrity and autonomy.⁵ In other words, a discussion of the social construction of scientific knowledge is necessarily a discussion of that knowledge as a product of the communities, societies, and circumstances that mark its production. Similarly, arguing that science is both a contestable text and a power field,⁶ Donna Haraway famously pointed out that any acquisition of knowledge is partially determined by adopting different views about the natural world. These perspectives, in turn, are influenced by gender, race, and social and cultural differences.⁷ Thus, the traditional ideas about scientific discoveries, truth, and progress held by most practising scientists are very different from the study of science as a set of historical phenomena and social practices. According to Haraway, the social constructionist point of view, informed by post-structuralist theories that identify power as being inevitably intertwined with domination, can provide a useful tool for dismantling the scientific discourse and its claim on truth. Furthermore, in her influential article “Situated Knowledges: The Science Question in Feminism and the Privileges of Partial Perspective”, Haraway writes that the physical, natural, biological, and even social sciences are a heterogeneous field of institutionalised knowledges used to effectively talk about the real world.⁸ More importantly, she remarks that we should not overlook the fact that the “object” of knowledge can easily be used as an instrument to disguise truth and facts to obscure economic and political interest.⁹

And Haraway is not the only one to challenge what counts as knowledge and to argue that what makes something knowledge is highly dependent on the local context.

⁵ Helen E. Longino, *Science as Social Knowledge: Values and Objectivity in Scientific Inquiry* (New Jersey: Princeton University Press, 1990), pp. 4-5.

⁶ Donna Haraway, “Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective,” *Feminism/Postmodernism*, ed. Linda J. Nicholson (Routledge, 1990), p. 577.

⁷ Donna Haraway, “A Cyborg Manifesto: Science, Technology and Socialist-Feminism in the Late Twentieth Century,” *Simian, Cyborgs and Women: The Reinvention of Nature* (Routledge, 1991), p. 110.

⁸ Haraway, “Situated Knowledges” p. 576.

⁹ *Ibid.* p. 591.

At present, there is a large amount of research literature on science as social practice and cultural text, putting the studies of science and technology in the interdisciplinary terrain. For example, the feminist perspective on science and technology offers a different angle about what counts as knowledge on a gendered context. Emily Martin, in her article "The Egg and the Sperm", has turned to the language of the science and argued that the cultural/social assumptions are often embedded in the language (and hence the production) of scientific knowledges. Martin critically discusses representations of biological facts and their social implications. She finds that the scientific stories about the egg and the sperm both reflect and reproduce to the traditional gender categories of man and woman. Scientific stories, in other words, are just another literary technique to describe a natural phenomenon. And culture is built into the language of science.¹⁰

All of these scholarly works show that "knowledges" and "facts" about cancer, much like other knowledges, are also situated and contextualised. These knowledges on cancer are always produced by positioned actors working in and between all kinds of locations and through a variety of research relationships. At the same time, they conceal salient details such as who does the research, who and what is being researched, who decides what is important to the general public, and how the research funded. In a way, this also partially explain how despite the fact that science and biomedicine have endeavoured to extract a single theory that explains cancer, reduced to a tidy formula from a complex network that includes genetic, environmental, and biological sciences, no such single theory of cancer has managed to stand as "universally true" scientific knowledge. We still have not singled out a gene, virus, or even a strong supporting environmental factor to comprehensively explain cancer or provide a systematic understanding of the cancer experience. As a matter of fact,

¹⁰ Emily Martin, "The Egg and the Sperm: How Science Has Constructed a Romance Based on Stereotypical Male-Female Roles," *Signs* (Vol. 16, No. 3, 1991), pp. 485-501.

theories about the disease inevitably subdivide into as many subcategories as there are subtypes of cancer with each “fact” only reflecting one aspect of the truth that comprises the heterogeneous production of scientific and biological knowledge. But first of all, let us look at what are being generated out of the ‘situated knowledges’ of cancer.

Medical Definitions

Medical definitions tell us what cancer is in scientific and medical terms. In this section, I show that even though these definitions are often portrayed as “scientific” and “objective”, they are made possible only at the expense of what is removed, namely, the embodied experience of the illness.

Cancer cannot be grouped under any single family of disease known to humankind. Unlike many other diseases, it cannot be explained by naming an external cause (such as E. Coli or the Human Immunodeficiency Virus) and it does not happen to everyone in the same way through the same course of events every time. For example, one patient’s breast cancer could be very different from her friend’s and would lead to very different results even under the same medical treatment. In essence, cancer is one name for many diseases caused by many things.¹¹ So what kind of malady is cancer? Cancer is not common like the flu, nor is it an attack on the body’s immune system. It is not even contagious, with the exception of some known cancers that are caused by viral infection.¹² Cancer is also not a neurological disease, as in the case of multiple sclerosis, nor is it caused by the progressive but irreversible

¹¹ Cancer can be caused by genetic factors, tobacco smoking, diet, lifestyle and habit, and even exposure to carcinogens in the environment (see “What Causes Cancer?” in the American Cancer Society website <http://www.cancer.org/Cancer/CancerCauses/index>, last accessed 19 July, 2012).

¹² For example, a DNA virus known as the Human Papilloma Virus (HPV) can increase the risk of cervical cancer and other cancers in the genital area in human beings. Primary liver cancer is also linked to the Hepatitis B and C viruses. However, this does not mean that a viral infection alone will cause cancer. The cellular events and the presence of the virus must occur simultaneously or the viral proteins must be expressed in an appropriate cell type or in an immunocompromised host (see Morris, Eddleston, and Crook’s “Viral Infection and Cancer,” *Lancet* (Sept 16, 1995), pp. 754-8).

wasting of bodily tissues as in the case of muscular dystrophy. It is not characterised by the failure of any bodily organs, such that placing the name of the organ in front of the word “cancer” does not necessarily indicate that something is wrong with the organ itself. For instance, breast cancer is not strictly a disease of the breast. The word “breast” only describes where the cancerous cells originated. Thus, “breast cancer” means that the cancerous cells originated in the breast tissue, but the breast itself is not malfunctioning or damaged in the way the heart can fail to work properly when an individual is suffering from a cardiovascular disease. Furthermore, cancer remains a highly individual disease that affects people indiscriminately. Although there are studies that show that certain races/genders/nationalities are more susceptible to certain types of cancer,¹³ to date there is no specific diet, lifestyle, or religious practice that can guarantee safety from cancer. Likewise, no race/gender/nationality as a whole has historically been known as cancer-free.

So far, I have provided an overview of what cancer is not, and attempts to determine what it is have proven equally uninspiring. During the 1960s, cancer was described in a well-known British medical textbook as:

A disease of multicellular organisms which is characterised by the seemingly uncontrolled multiplication and spread within the organism of apparently abnormal forms of the organism's own cells.¹⁴

¹³ See, for example, Shelia Hoar Zahm and Joseph F. Fraumeni, Jr.'s “Racial, Ethnic, and Gender Variations in Cancer Risk: Considerations for Future Epidemiologic Research,” in *Environmental Health Perspectives* (Vol. 103, Nov 1995, Supplement 8), pp. 283-286, or Frederica P. Perera's “Environment and Cancer: Who Are Susceptible?” in *Science* (Vol. 278, No. 5340, 1997), pp. 1068-1073. Furthermore, there are researches studying the relationship between the cancer rate of a specific cancer and ethnicity and sex, such as “Skin Cancer Rates by Race and Ethnicity,” in *Centers for Disease Control and Prevention* (<http://www.cdc.gov/cancer/skin/statistics/race.htm>, last accessed 30 July 2012), and Carolyn M. Dresier et. al.'s “Gender Differences in Genetic Susceptibility for Lung Cancer,” in *Lung Cancer* (Vol. 30, No. 3, 2000), pp. 153-160.

¹⁴ F.J.C. Roe, “Cancer as a Disease of the Whole Organism,” *Biology of Cancer*, eds. E.J. Ambrose and F.J.C. Roe (London: D. Van Nostrand Company Ltd., 1966) p. 28.

Almost half a century later, a sample definition can be found in another textbook written by Robert Weinberg, a renowned U.S. cancer researcher credited with the discovery of the first human oncogene:

Tumours are created by cells that have lost the ability to assemble and create tissues of normal form and function. Stated more simply, cancer came to be viewed as a disease of malfunctioning cells.¹⁵

Perhaps at first glance we can say that the earlier definition is more focused on the “action” of what cancer does while the more recent version more effectively describes the nature of the disease. Given the number of scientific discoveries and technological innovations that have occurred between then and now, however, it is only natural for the lay public to expect a more drastic difference in cancer’s description, perhaps involving an improved understanding of the causes or how it can be prevented. Thus, the lack of improved insight into the knowledge of cancer also tells us that nothing has successfully changed, reversed, or even prevented these cell malfunctions – then or now.

If the medical language in textbooks is for a specific type of readers (for example, medical students, other health care professionals, etc), perhaps the inexhaustible wealth of information available online is more open to the general (lay) public. Page after page of hits appear upon entering the question, What is cancer?, into a search engine. Here is a sample non-textbook definition of the disease:

Cells in different parts of the body may look and work differently but most reproduce themselves in the same way. Cells are constantly becoming old and dying, and new cells are produced to replace them. Normally, cells divide in an orderly and controlled manner. If for some reason the process gets out of control, the cells carry on dividing, developing into a lump which is called a tumour.

...

A malignant tumour consists of cancer cells that have the ability to spread beyond the original area. If the tumour is left untreated, it may spread into and

¹⁵ Robert A. Weinberg, *The Biology of Cancer* (New York: Garland Science, 2007) p. 27.

destroy surrounding tissue. Sometimes cells break away from the original (primary) cancer. They may spread to other organs in the body through the bloodstream or lymphatic system.¹⁶

Nonetheless, whichever definition we choose, textbook or otherwise, the same series of questions remain unanswered: What, exactly, are the reasons that cells are dividing abnormally?; How do you stop cell division from going out of control?; and Is it preventable? Because these definitions are mainly interested in describing the pathology of cancer, they give the impression that there is no connection between the disease and the body it inhabits. Is this because the “multiplication”, “spreading”, “malfunctioning”, and “invasion” of cells do not affect the feelings or sensations of the host body? In other words, the need for a unifying definition of cancer actually opens up more questions regarding the disease and the physical experience of it. And this immediately brings us to how the communication between the patient and the disease is presented in a particular scientific discourse.

Signs and Symptoms

In conventional medicine, the signs and symptoms of an illness are sensations and perceptions within the body that we, in turn, interpret as uncomfortable, strange, or suggestive of something life-threatening. Signs and symptoms are not one and the same. In most cases signs and symptoms are inseparable, with signs being the objective evidence of a disease while symptoms are subjectively sensed and felt by the patient, and it usually takes both for meanings to be conveyed properly.¹⁷ Signs and symptoms are important because they are usually accompanied by a sense of discomfort or abnormality within the body, which alerts the individual to determine the source of the sensations. Typically these unpleasant or abnormal sensations will

¹⁶ From “What is Cancer,”

<http://www.macmillan.org.uk/Cancerinformation/Aboutcancer/WhatisCancer.aspx> (last accessed 9 Dec 2010).

¹⁷ For popular medical definitions of signs and symptoms, see http://www.medicinenet.com/symptoms_and_signs/article.htm or <http://www.medicalnewstoday.com/articles/161858.php>

arouse a sense of worry or fear. Even though some symptoms and physical conditions such as headaches, osteoporosis, or high-cholesterol are now medicalised as diseases and there are some symptoms, such as chronic pain or fatigue, that can occur outside any identifiable disease, we have learned to gauge and interpret the seriousness of the discomfort we feel and decide whether we should seek medical attention. Signs and symptoms, to put it succinctly, are a form of communication between the person and the disease.

We have learned, from experience, how to interpret these sensations and respond accordingly. We have always relied on our body's reaction – whether to a virus or to an organ malfunctioning – and the resultant feelings of general discomfort, which vary from individual to individual in terms of intensity, are what “being ill” means to us. Take influenza for example. It is known to be caused by a virus and most people have probably experienced it before, but even with an illness as common as the flu we must rely on the intricate workings of our bodies and our memories of previous experiences to tell us when our body is “under attack” by a virus. There is no bodily sensation that accompanies a virus when it first invades our cells. It is not until we begin to sneeze to clear our nasal passages of irritants or cough to expel excessive mucus from our throats that we suspect influenza. Hence, sneezing and coughing are both flu symptoms, and it is from these manifest signs and symptoms that doctors and physicians can make a diagnosis and suggest treatment. In other words, manifest signs and symptoms are the result of the agents' interaction with the host body. In their research on the role of feeling in relation to health, illness, and recovery, Telles and Pollark interviewed laypersons about how “feeling ill” is a crucial criterion for illness. Their results revealed that an explicit conception of health and illness is often defined in terms of feeling. In fact, feelings are not only an initial

indicator of illness, but are also an indicator throughout an illness.¹⁸ In addition, Telles and Pollark found that “feelings” are also used by individuals to deny the presence of any illness symptoms through claims that they feel “OK” or “normal” to avoid seeing a physician.¹⁹ This suggests that feelings, whether they deviate from a normal, desired capacity or from normal bodily experience, can either reflect or repress their bodily condition until it is legitimated by a medical professional with a diagnosis.

However, when applied to cancer, it creates a problem in which the presence of signs and symptoms is out of sync with the body’s reaction to the disease. Rather than forewarning the body about the onset of an illness, the signs and symptoms of cancer often tell a belated story. For example, how does one know exactly when the first mutation and abnormal growth within one’s cells takes place? If our body responds by coughing and sneezing, and this spreads the virus via the tiny droplets of moisture that we produce when our respiratory tract is infected, then how can medical knowledge and our feelings reflect the cancerous condition? In short, what does it feel like to have cancer?

If signs and symptoms are the ways in which our bodies communicate with disease, then in cancer, this communication can only be understood as intrinsically flawed. First, cancer cannot be felt. Contrary to what most people believe, pain is not one of the symptoms of most common cancers, such as breast or lung cancers.²⁰ Second, cancer cannot be seen with the naked eye. Although it is common to describe

¹⁸ Joel Telles and Mark Harris Pollark, “Feeling Sick: The Experience and Legitimation of Illness,” *Social Science and Medicine, Part A: Medical Sociology* (Vol. 15, No.3, Part 1, 1981) p. 245.

¹⁹ *Ibid.*, p. 250.

²⁰ It is a misconception that cancer is intrinsically painful. It only causes pain if the cancer cells invade or press on surrounding tissue that is supplied with nerves. For signs and symptoms, see “Understanding Lung Cancer – Causes and Symptoms,” *Australia Cancer Council* (<http://www.cancercouncil.com.au/editorial.asp?pageid=46>) for lung cancer and “Fact File: Breast Cancer,” *ABC Health & Wellbeing* (<http://www.abc.net.au/health/library/stories/2005/09/01/1829103.htm>) for breast cancer.

cancer or a tumour as a growing lump, as if it were something tactile or visible, such growth only happens in tissues where there are cells that line the walls of cavities and channels. The tumour then spreads by invading the surrounding cell layers. However, none of this necessarily means that the lump can be felt or detected at an early stage, nor are tumours a common sign in every type of cancer. To make things even more complicated, there are different symptoms for each type of cancer. For example, according to the American Cancer Society (ACS) website, the general signs and symptoms of cancer include: unexplained weight loss, fever, fatigue, pain, and skin changes. More specifically, the primary symptoms of stomach cancer are nausea and weight loss while for lung cancer, the symptoms are shortness of breath and coughing. Fatigue can indicate leukaemia but, in reality, how often does feeling tired alarm us? How do we differentiate between fatigue and general tiredness? It is equally unlikely that we will notice “unexplained” weight loss. Indeed, we are likely to perceive these types of subtle symptoms as something that will pass, or as “nothing at all”. Feelings are no longer useful here because our judgement is overridden by the rationalisation that we should not “make a big deal” out of small discomforts such as tiredness. In fact, one can only feel the very first symptom or sign of cancer in hindsight as a simulation of other non-threatening disorders such as influenza, indigestion, or other run-of-the-mill, stress-induced abnormal sensations. Even if we try to stay alert about these signs and symptoms, such as by regular self-examination or getting screened for cancer after a certain age,²¹ we also know that there is no way to prevent it from occurring in the first place. Interestingly, the ACS also states that cancer is a disease group that “can cause almost any sign or symptom”, but it is quick to assure that

²¹ For example, the Australian government introduced the National Bowel Cancer Screening Programme in 2006 for people turning 50, 55, and 65 years of age. There are also screenings for cervical and breast cancer. See: <http://www.cancerscreening.gov.au/>

“Treatment works best when cancer is found early”.²² According to the two above statements, we can only gather that cancer is like a dark shadow that vanishes when there is no source of light. Unless we irrationally relate all of our bodily sensations to cancer all the time, cancer will always be shrouded in its own darkness.

Signs and symptoms are our body’s most natural way of warning us that something is wrong, but the more we understand the signs and symptoms of cancer, the more we know that they are merely messages that typically arrive “after the fact”. Although epidemiologists have sought to incriminate carcinogenic exposure as the culprit that causes cancer and genetic scientists have established links to our genetic susceptibilities, cancer does not just happen. In fact, one of its characteristics is its extended indolence, such that the longer we live, the longer it lives with us. Take prostate cancer as an example. This common form of cancer is known to be highly variable in its clinical course. In the majority of cases it occurs in elderly men. It is also true that more men die with prostate cancer than die of it.²³ It is precisely because it is a disease that lives with the body rather than against it that the eventual onset or manifestation of cancer signs and symptoms is always a bit too late. Similar to a burglar alarm that only sounds after the burglars have broken into and settled inside the house, the signs and symptoms of (prostate) cancer are a form of miscommunication. Rather than understanding cancer as a disease with recognisable signs and symptoms, it is more suitably described as a phenomenon characterised by a disjointed “here” and “now” because its presence “now” is not necessarily aligned with what is happening “here”.

²² American Cancer Society, “Signs and Symptoms of Cancer” (<http://www.cancer.org/Cancer/CancerBasics/signs-and-symptoms-of-cancer>). Last accessed 17 Nov 2010.

²³ Siddhartha Mukherjee, *The Emperor of all Maladies: A Biography of Cancer* (London: Four Estate: 2011) p. 211.

In addition to this disjointed “here” and “now”, cancer is also characterised by signs that are out of sync with symptoms. Breast cancer is another example. Until a woman notices that there is a lump in her breast, she will not realise that she may have cancer. It is a sign, rather than a symptom, because unlike feelings such as fatigue, pain or nausea, a lump distinctively points to a certain kind of anomaly; perceptible evidence of a type of breast cancer. It triggers alarm and deep concern, perhaps even fear, in the woman and she will not hesitate to seek prompt medical advice. It is at this point that she might begin to wonder if her recent weight loss might not be the result of stress or her diet after all. In other words, when cancer finally makes itself known through signs, it often belies the real beginning of the story. In the case of breast cancer, the direct, unambiguous discovery of a lump in the breast tissue can only indicate the possibility of breast cancer and is less likely to be mistaken than a skin lesion or the signs and symptoms of a stomach ulcer. The only thing that a lump fails to tell its host is whether it is malignant or benign in nature. Nonetheless, it serves as an indication that a disorder is present in the body. This specific sign in breast cancer announces: I have made my presence known to you. It does not, however, announce that cancer has arrived. The same can be applied to other cancers. A person who coughs may not take it as a sign of lung cancer, but it becomes a sign when there are streaks of blood in his sputum. The cough then becomes an early symptom. Similarly, a person is more alarmed when there is abnormal haemorrhage in her faeces, because it can be taken as a sign of colon cancer. Suddenly the earlier bouts of constipation and diarrhoea begin to make sense because they are now understood as symptoms of this type of cancer. Compared with more general symptoms, such as fatigue and pain, the presence of blood, like a lump in the breast tissue, is visible and quantifiable, which makes it possible to depict the “dark shadow” of cancer in a “material” sense.

As we can see, as much as we rely on signs and symptoms to identify a disease, what cancer's signs and symptoms fail to indicate as part of the "truth-marker" in the scientific discourse is that they happen in an untimely manner, with the presence of signs becoming an alibi for a "now" that has slipped away. When cancer is belatedly visible "now", it can only tell the history of the "here" with the benefit of hindsight. And this, ultimately, will affect our understanding of the cause-and-effect theory of cancer.

Cause and Effect

Similar to signs and symptoms, cause and effect are typically what we rely on to understand and explain the *origin* of an illness or a disease. Alternatively, it can be read as an epic story in which the cause and the effect serve as bookends to frame the victory of science and its conquest. Biomedical advances in past centuries have tried to understand human bodies as machines.²⁴ Unsurprisingly, the anatomical approach to illness suggests that we, like machines, can be fixed – that our problems can be reversed or removed.²⁵ Thus, the linear perspective of the cause and effect model of illness has been useful in teaching us a great deal about disease in the past. For example, we know that the common flu is caused by different types of viruses and that a toothache can be caused by a number of dental problems such as dental cavities, gum disease, or cracked tooth as the result of bacteria combining with food debris to produce acids that destroy the surface of the teeth. Having a reductive theory to explain a disease enables us to learn how to effectively prevent the disease. We know

²⁴ The image of man as machine is rooted in seventeenth-century thought beginning with philosophical observation by Descartes, La Mettrie and others. Drew Leder writes that "the reliance of our medical education system on selecting and training 'scientist'; the increasing focus on medical technology, using machines to fix the body-machine; the burgeoning of specialisation, allowing doctors to focus on one part of the machine, etc. And it wasn't until the twentieth century that alternative philosophical models have emerged to critique modern medicine's approach to the illness experience. For instance, Foucault suggests that by conceiving the human body as machine, then these bodies are docile and can be manipulated for political and social functions. See Drew Leder's *The Medical Thought and Practice*. Ed. Drew Leder (Kluwer Academic Publishers, The Netherlands, 1992), p. 4.

²⁵ Gordon Waddell, et al., "Symptoms and Signs: Physical Disease or Illness Behaviour?" *British Medical Journal* (Vol 289, 22 Sept, 1984), p. 740.

to cover our nose and mouth when coughing and sneezing to prevent the spread of germs and to brush our teeth at night to prevent tooth decay. However, some diseases are more “epic” than the others. Take tuberculosis as an example. It was only in 1882, a few years after his own proposal of the germ theory, that Dr. Robert Koch discovered the bacterium that caused the highly contagious and fatal disease. Because his germ theory stated that all germs and microbacteria are the cause of many known diseases, the bacteria mycobacteria tuberculosis that Koch discovered was conveniently blamed for single-handedly causing the dreaded disease. In the 1940s, antibiotics were discovered and the disease was finally brought under control. Although tuberculosis is still a major health problem around the world, knowing that the bacteria is airborne (so preventive measures can be taken) and that it can be treated with a combination of antibiotics has made it much more manageable.²⁶

With an identified culprit and a definite cure bookending the story of the history of a scientific discovery, cause-and-effect serves as a framing device when telling the scientific story of an illness, but what can it say about cancer and its scientific/medical achievements? Cancer was first diagnosed and documented by the Ancient Greeks. Hippocrates believed that it was a result of excessive black bile that was incurable unless discovered at a very early stage. Although to this date the existence of “black bile” cannot be proven, during the mid to late nineteenth century, all tissues and complex organisms were discovered to have come from fertilised eggs. This has a significant impact on the scientific knowledge of cancer because it leads us to understand that “all the cells in the body of a complex organism are members of cell lineages that can be traced back to the fertilised egg. And conversely, it is the fertilised egg that spawns all the cells in the body, doing so through repeated cycles of

²⁶ “Tuberculosis,” in *University of Maryland Medical Centre* web page. See <http://www.umm.edu/altmed/articles/tuberculosis-000165.htm> (last accessed 09 Sept 2011).

cell growth and division".²⁷ Thus, it becomes an important foundation for the biological origin of cancer because we are now able to view it at a molecular level and explain it via its cellular organisation. Discovering that cancer originates in the cells does not, however, offer us any insight into to what causes cancer.

According to Robert Weinberg, cancer is caused by a series of genetic changes that result in a group of cells replicating out of control. A tumour then eventually becomes malignant when the cells accumulate and invade the surrounding tissues. In many cases, these tumour cells establish new growth by migrating to a different distant site. As we are still wondering what causes the genetic change, let us not forget that underlying the progression of a cancerous cell are many unknown and varied abnormal cellular changes whose relevance to the development of cancer it is virtually impossible to determine. In addition, different specialised cell types spawn different human cancers. For example, epithelia give rise to carcinomas, which is the most common form of human cancer. Sarcomas are derived from the various connective tissues while neuroectodermal tumours result from the cells that form the various components of the central and peripheral nervous systems.²⁸ In addition to cell types, there are also various types of cell growth, including hyperplastic, metaplastic, dysplastic, and neoplastic (a term that indicates growth that invades underlying tissues that is mostly reserved for use with the word "cancer" by most clinical oncologists).²⁹ Even in the case of neoplasia, there are different and highly variable latent intervals. To an extent, the lack of a reductive theory to explain cancer is also the result of the fact that the unrestricted growth of cells that characterises cancer can be both the cause and the effect of the disease. Abnormal cellular growth is the cause if we take a step back and view it as a biological manifestation of the

²⁷ Robert A. Weinberg, *The Biology of Cancer* (New York: Garland Science, 2007), p. 26.

²⁸ Weinberg, *The Biology of Cancer*, pp. 30-35.

²⁹ *Ibid.*, pp. 36-39.

failure of our DNA to regulate cell growth and division. However, if we consider that it is the presence of carcinogens (something that can be found even in the best of our food and water unpolluted by pesticides and herbicides)³⁰ and many other external factors, then the abnormal growth of cells as an effect seems a better fit. With this understanding, it is no surprise that even when we remove carcinogenic agents such as asbestos, tobacco smoking, PVC, and a host of others from the equation, we are still not left with a straight-forward cause of cancer as an effect.

Furthermore, it is this failure to find a unifying, coherent framing device for the scientific story of cancer that eventually amplifies the contradictory and dissonant voices of science. Because cancer is a class of diseases, rather than a single disease, a singular, coherent theory that speaks for all types (and subtypes) of cancer does not seem possible, despite genetic scientists' efforts to trace its origin. As a result of the subsequent identification of the different genes responsible for the development of the different cancer types and subtypes, the possible causes of cancer multiply exponentially. For instance, science has successfully identified and isolated the p53 tumour suppressor gene that is believed to be responsible for BRCA1-type breast cancer. Unfortunately, there are 15,000 known genetic variants of this gene. In addition to the genes that are responsible for certain types of hereditary cancer (and many more waiting to be discovered), there are also genes that are responsible for the migration of cancer cells within the body, which causes metastasis.³¹ This makes the actual biology too complex to support the statement that such a mutation directly "results" in cancer. For example, less than 50% of breast cancer involves the mutations in p53. Hence, in breast cancer, it often takes a combination of several

³⁰ Richard C. Lewontin, *Biology as Ideology: The Doctrine of DNA* (New York: HarperPerennial, 1992), p. 45.

³¹ See "MIT Researchers Identify the Genes Responsible for Cancer Cells' Ability to Migrate Within the Body," in MIT News (August, 2, 2000) <http://www.mit.edu/newsoffice/2000/metastasis.html> (Last accessed 9 Jan, 2012).

“pathways” for mutations to happen. Knowing that this certain subtype of breast cancer is a disease of the gene does not mean that all breast cancers are caused by the same gene, or that they are genetically related.

Therefore, from smoking tobacco to radiation or an unhealthy diet to genetic mutations, these “causes” of cancer are conditional at best. A more recent example comes from an article published in the November 2008 issue of *Scientific American*, which claims that there is a strong association between chronic inflammatory conditions in a particular organ/tissue and the development of cancer in that organ/tissue. The author argued that the longer the inflammation persists, the higher the risk of associated carcinogenesis. How cancer occurs is subsequently described and explained in a causally-related manner, such that “genetic damage is the match that lights the fire and the inflammation is the fuel that feeds it”.³² In fact, the scientific data supporting this claim are so convincing that textbooks have been revised accordingly³³ and the “mysteries of cancer” are expected to be unravelled in due course. However, as we wait for the further development of this new theory, we must bear in mind that a “strong association” does not necessarily mean a direct cause-and-effect relationship. Chronic inflammation is only a risk factor, much like tobacco smoking and unhealthy diet in people who already harbour a heightened predisposition for cancers such as ulcerative colitis (UC) and Crohn’s disease of the colon – the major forms of idiopathic inflammatory bowel disease.³⁴ Risk factors, in turn, are not direct causes and identifying chronic inflammation as one risk factor only means that there is one more thing the lay public should remain vigilant about.

³² Gary Stix, “Is Chronic Inflammation the Key to Unlocking the Mysteries of Cancer?” *Scientific American* (Sunday, 9 November 2008). Source:

<http://www.scientificamerican.com/article.cfm?id=chronic-inflammation-cancer>

³³ According to the article, Robert Weinberg revised his textbook *The Biology of Cancer* in 2006 to highlight this finding.

³⁴ Lisiane B. Meira, “DNA Damage Induced by Chronic Inflammation Contributes to Colon Carcinogenesis in Mice,” *The Journal of Clinical Investigation* (Vol. 118, No. 7, 2008), pp. 2516-2525.

Regarding our need for a logical explanation of what is happening to our bodies, science writer and biologist Richard Lewontin remarks that it is actually our “ideological prejudice” that drives us to seek a reductive, coherent theory that accounts for all matters of health and illness. We believe that everything happens for a reason and that it is science’s (or biology’s) job to give us a logical explanation. However, there are many examples throughout history of a cause not necessarily corresponding with an effect and things do not always follow in a logical manner. In the example of tuberculosis and other infectious diseases, the germ theory has led us to trust that as long as there are antibiotics and other chemical agents that can effectively launch a counter-attack against the responsible microorganisms, we will be protected from (dying of) these diseases. However, despite the strong causal theory behind these diseases that used to plague humankind, Lewontin argues that modern scientific medicine has not played a significant role in the falling mortality rate from diseases like bronchitis, pneumonia, and tuberculosis during the nineteenth century. He writes: “There was no observable effect on the death rate after the germ theory of disease was announced in 1876 by Robert Koch. The death rate from these infectious diseases simply continued to decline as if Koch had never lived.”³⁵ In other words, while the cause-and-effect view has long been taken for granted, particularly in the practice of science concerning matters of health and disease, it also implies that such a view must relegate all other possible but non-medically related causes as less important, even irrelevant, in order to fit into a simple scheme, when in fact the causes of a problem could be manifold. This is similar for cancer. In his analysis of how the philosophy of science has been mistakenly applied to the understanding of the nature of illness, Harold Kincaid observed that most leading cancer research worldwide has only been able to produce piecemeal causal explanations for the

³⁵ Lewontin, *Biology as Ideology*, p. 44.

disease.³⁶ According to Kincaid, what we have now is hit-or-miss treatment for cancer patients with radio- and chemotherapy, used separately or in conjunction, only working in some cases.³⁷ Moreover, because no one knows exactly how many genes are in the human genome, it is impossible to analyse each gene individually for a likely cause of cancer. Therefore, even though a mutant gene might be considered the causative factor of a cancer, it is more like “finding a needle in the haystack, with the haystack of an unknown size”.³⁸

While we are blaming the bacteria for causing tuberculosis, we are conveniently forgetting to consider the conditions that characterised the nineteenth century, including unregulated industrialisation, capitalism, and poorly ventilated and unsanitary work conditions in factories. These are, as we now know, the necessary environmental conditions for tuberculosis as Lewontin further argues:

[If we think of health in this way], then we might be justified in claiming that the cause of tuberculosis is unregulated industrial capitalism, and if we did away with that system of social organisation, we would not need to worry about the tubercle bacillus.³⁹

Similarly, while we are busy with blaming our genes for their deadly mutations, the simplified theory of cause and effect also serves as a reminder for us to ask ourselves these questions: can we also look at the other external conditions that could be responsible for causing cancer, and if modern biology is exclusively looking for the

³⁶ Harold Kincaid, “Do We Need Theory to Study Disease?” *Perspectives in Biology and Medicine* (Vol. 51, No. 3, Summer 2008), p. 373.

³⁷ There has been research that has proven that chemotherapy is not the most effective way of treating cancer due to the elevated toxicity contained in the drugs. See A.S. Braverman, MD, “Medical Oncology in the 90s,” in *Lancet*, (Vol. 337, 1991), p. 901 and Walter Last, “The Diversity and Effectiveness of Natural Cancer Cures,” in *The Ecologist* (Vol. 28, No. 2, March/April 1998) pp. 117-122. Assessing the role of chemotherapy in lung cancer treatment is even more difficult because even with the available drug combinations it has proven to be of modest value in small cell-type lung cancer. See David T. Carr, “Lung Cancer: From Triumph to Tragedy,” in *International Journal of Cell Cloning* (Vol. 9, 1991) pp. 548-558.

³⁸ Weinberg, *The Biology of Cancer*, p. 54.

³⁹ Lewontin, *Biology as Ideology*, p. 42.

cause for an effect, what happens to the other causes that cannot be subjected to manipulation and interference for the benefit of the theory itself?

Numbers and statistics

Numbers and statistics are considered one of the most reliable components for a scientific discourse as they represent empirical evidence based on a rigorous and valid methodology. However, even numbers are not necessarily telling a straightforward, uncontentious story of cancer. For example, according to the Cancer Council in Australia, “An estimated 114,000 new cases of cancer were diagnosed in Australia in 2010” and “nearly 15,000 more people die each year from cancer than did 30 years ago, which is due mainly to population growth and ageing”. The source is quick to add that “the death rate (number of deaths per 100,000) has fallen by nearly 15 per cent” in that time.⁴⁰ The numbers in these three statements tell us that although more people are diagnosed with cancer and have died from it (because we are living longer), the cancer’s mortality rate has actually improved over the past three decades. Does this mean that biomedicine has been effective in rescuing us from cancer? Is it true that the only reason more people are diagnosed with cancer is because of our increased longevity? Samuel Epstein, an outspoken American professor of environmental and occupational medicine and Chairman of the Cancer Prevention Coalition in the U.S., argues that this is only what cancer institutions such as the ACS and the National Cancer Institute (NCI) would like us to believe.⁴¹ He claims that because cancer incidence rates are age-adjusted, such that the individual factor of age and longer lifespan is not enough to explain the increased cancer rate, cancer incidences have actually escalated to epidemic proportions, particularly for

⁴⁰ Cancer Council Australia, “Facts and Figures”

(<http://www.cancer.org.au/aboutcancer/FactsFigures.htm>). Last accessed 27 May 2012.

⁴¹ Samuel Epstein is recognised as outspoken cancer expert on avoidable causes of cancer, particularly unknowing exposures to industrial carcinogens in the environment. He is also known for being a critic of mainstream medicine and cancer establishment for their fixation on damage control.

non-smoking related cancers. In an interview, Epstein provided his own sets of numbers: Non-Hodgkin's Lymphoma has gone up by 100%, breast cancer by 60-65%, testicular cancer – particularly between the ages of 28 and 35 – has gone up by 300%.⁴² He also suggests that the reason for these increases in cancer incidences lies in our environment. Thus, much like tuberculosis, Epstein believes that cancer is a biological illness that reflects the pathology of our environment and society.

Indeed, it is only by considering the environment as a factor that we can explain other sets of statistics. Epidemiologic studies in past decades have long provided evidence that our environment is the dominant determinant of inter-country variations in cancer incidences. In 1992, the NCI published a study that compared and compiled the cancer incidence rates of five continents. Unsurprisingly, the results showed that the incidence rates were not distributed evenly around the world. For example, the incidence of lung cancer among men is 119.1 per 100,000 in New Zealand Maoris, and only 1 per 100,000 in the Gambia. Similarly, there are about 62.2 per 100,000 cases of lung cancer among women in New Zealand Maoris and only 1.4 per 100,000 in Madras, India. In the case of stomach cancer, the incidence rate ranges from as high as 93.3 per 100,000 males in Japan to as low as 2.1 per 100,000 males in India.⁴³ According to the NCI, these rates are age-adjusted, such that the incidence of cancer due to a generally longer lifespan is not one of the factors affecting the rates.

The debate surrounding the environmental causes of cancer is not recent. The earliest claims can be traced back as early as the 1960s, almost a decade before then U.S. President, Richard Nixon, signed the National Cancer Act in 1971. At that time,

⁴² "Cancer: It's a Growth Industry," *Third World Traveller*, Interview by David Ross, 2003 (http://www.thirdworldtraveler.com/Health/Cancer_Growth_Industry.html) Last accessed 24 Oct 2010.

⁴³ See "International Range of Cancer Incidence" by National Cancer Institute's Surveillance and Epidemiology and End Results (<http://www.seer.cancer.gov/>) Website last accessed: 6 January 2011.

American biologist and nature writer, Rachael Carson, had already claimed in her seminal work, *Silent Spring*, that the use of chemicals and poisons (such as DDT and other varieties of pesticides) for agricultural and industrial gains caused cancer. She argued that “for the first time in the history of the world, every human being is now subjected to contact with dangerous chemicals, from the moment of conception until death.” Carson also insisted that because these chemical substances have detrimental effects on the environment, we should not tolerate “the chemical death rain to fall as though there were no alternatives”.⁴⁴ Carson’s accusation of pesticide abuse in the environment worked nicely with mutagen theory. A mutagen is anything that causes a mutation (a change in the DNA of a cell) that results in damaged cells and/or causes diseases like cancer.⁴⁵ Mutagen theory works effectively with carcinogen theory to explain causes of cancer because they successfully link internal and external causes for the first time. Since the link between radiation and genetic mutation was established in 1928 by geneticist Hermann Joseph Muller, mutagens appear to be a perfect fit for explaining the aberrant behaviour of cancer cells and their carcinogenesis.⁴⁶

Mutagens and carcinogens point to what is outside the body that might cause cancer. However, in the 1970s, Bruce N. Ames developed and conducted the Ames test with this research team at the University of California, Berkeley to assess the mutagenicity of chemical compounds. Three years later, the Ames test provided evidence of the mutant genes theory by showing that many carcinogens can act as mutagens. Other similar scientific experiments have shown that a number of human cancers can be attributed to the food or mutagenic substances we experience in our everyday lives. However, not all carcinogens tested positive in these tests, which

⁴⁴ Rachel Carson, *Silent Spring* (Boston: Houghton Mifflin, 1962), p. 12.

⁴⁵ <http://www.cancer.gov/dictionary?cdrid=601170>

⁴⁶ For example, see Fred Bunz’s *Principles of Cancer Genetics* (Springer, 2008), pp. 19-23.

indicates that not all carcinogens are mutagenic. Although all compounds that are mutagenic are likely to test as carcinogenic (directly cancer-causing), the converse is not true. In fact, arguing that epidemiological studies have already identified environmental pollution as only secondarily contributing to cancer risks, Ames et al. replied that Carson was wrong in believing that the chemicals we come into contact with are mostly dangerous: "Carson thus lacked perspective about the wide variety of naturally occurring chemicals to which all people are exposed and did not address the fact that, outside the workplace, exposures to synthetic pollutants are extremely low relative to the natural background."⁴⁷

Today, it is still unclear whether Carson exaggerated the cancer threat and its link to pesticides by misinterpreting the cancer statistics to support her own findings and claims, or whether she was correctly intuiting the threat. The inherent contradictions hidden in these numbers and statistics are aptly noted by Caula A. Beyl:

Cancer statistics are not easy to interpret if cancer death is considered apart from incidence, and the data can be obfuscated even further by making a critical examination of the statistical base used.⁴⁸

One thing we can gather from these cancer statistics is that as much as they are empirical evidence from past cases, they do not necessarily predict the future empirically. Cancer survival rate is a good example. Originally intended to inform patients of the survival statistics for people in similar situations, these numbers are commonly taken as an indication of how fatal a cancer is. According to the ASC, the five-year survival rate for stage I colon cancer is 74% and for people with stage IIA is 67%.⁴⁹ Although this does mean that 74% and 67% of people with stage I or stage

⁴⁷ Bruce N. Ames and Lois S. Gold, "The Causes and Prevention of Cancer: Gaining Perspective," *Environmental Health Perspectives Supplements* (Vol. 105, Issue Suppl. 4, 1997), p. 868.

⁴⁸ Caula A. Beyl, "Rachel Carson's Fight Against Pesticides," *The Environment*, ed. William Dudley (Farmington Hills, MI: Greenhaven Press, 2006), p. 99.

⁴⁹ "What are the survival rates for colorectal cancer by stage?" *American Cancer Society*, <http://www.cancer.org/Cancer/ColonandRectumCancer/DetailedGuide/colorectal-cancer-survival-rates> (last accessed 27 May 2012).

IIA colon cancer, respectively, have lived at least five years after their cancer was diagnosed, the numbers are also from a particular study done at a particular time with a particular group of people in a particular region. Reading further into these numbers reminds us that these are observed survival rates, which means that people diagnosed with colon cancer may have died later from some other cause. Thus, these numbers do not necessarily reveal the “facts” about an individual’s specific cancer, and therefore, they should not be taken as the only way to predict one’s own prognosis, let alone as a tool to predict what will happen in the future.

Cancer Politics

The reality of cancer is more than what the numbers show, or how it is defined/explained. It is also the sum total of what is being left out in the quest for a theory that fits a clean scientific description. What is reduced/displaced/marginalised, I argue, will inevitably emerge again in other forms. One of these forms is the politics of cancer as a site of struggle between powerful institutions and the welfare of the population.

The phrase “the politics of cancer” was first used by Samuel Epstein in his book of the same title.⁵⁰ According to Epstein, the politics of cancer comprise the conflicts of interest between cancer research institutions, the pharmaceutical industry, and the general public. In his view, “being political” about cancer means that public health experts and professionals should lobby the government and Congress to remove avoidable carcinogenic exposures by law or regulation. Epstein also supports laws that criminalise corporations that knowingly introduce new carcinogens into the environment. This particular viewpoint is important in liberating the definition of “scientific” knowledge of cancer from the realm of biomedicine into the social and

⁵⁰ See Samuel S. Epstein, *The Politics of Cancer* (San Francisco, Sierra Club Books, 1978) and *The Politics of Cancer Revisited* (New York: East Ridge Press, 1998).

political aspects of the disease. It allows the general public be critical of what they are told about cancer as well. In this sense, we can even say that the politics of cancer works along with the changed definition of what it means to be a member of the pay public. Today, the so-called "lay" public is no longer passively receiving information. They can educate themselves on their conditions on the Internet, and join online support groups so that they are becoming informed and empowered health consumers. In fact, as Peter Conrad observes, the public is becoming more articulate and critical of medicine's expansion. And especially due to the rise of the use of the Internet there is what he termed "online social movements". What this means is that "groups move beyond experiential exchange and support to advocate for an alternative interpretation of an illness or the recognition of a previously unknown condition as an illness".⁵¹ As such, it enables the public to become not just participants but also to influence public policy regarding cancer research.

Admittedly, political decisions can make a difference in life and death matters when they have control over what can be known/revealed and what is hidden about a disease like cancer. The fact that cancer is, according to Epstein, "avoidable" and the cancer war can be "winnable" seems to promise that as long as we are able to find out what is behind the researches of the cancer establishment, then there will be hope. However, to what extent can the "informed and empowered" public influence these decisions? For example, when Epstein explains how exposure to environmental and occupational carcinogens can cause cancer, how much and in what direct ways can the public interfere? According to his argument, although there are avoidable causes, instead of finding ways to prevent them, the American Cancer Society (ACS) and

⁵¹ Peter Conrad and Cheryl Stults, "The Internet and the Experience of Illness," in *Handbook of Medical Sociology*. Ed. Chloe E. Bird, Peter Conrad, Allen M. Fremont, and Stefan Timmermans (Tennessee: Vanderbilt University Press, 2010), p. 184.

National Cancer Institute (NCI) – the largest cancer research institutions in the U.S. – only allocate US\$1 million to cancer prevention and education. Epstein explains:

Giant corporations, which profited handsomely while they polluted air, water, the workplace, and food with a wide range of carcinogens, remain greatly comforted by the silence of the ACS. This silence reflected a complex of mindsets fixated on diagnosis, treatment, and basic genetic research, together with ignorance, indifference, and even hostility to prevention. These mindsets are also coupled with major conflicts of interest.⁵²

Epstein argues that we are now losing the “winnable war” on cancer because the cancer establishment is fixated exclusively on damage control and genetic research, and as a result of the aforementioned major conflicts of interest. In a separate article, Epstein and Lisa Gross, another public health expert, provide their own evidence of how the mammography industry not only conducts research for the ACS, but also serves on its advisory boards and donates considerable funds:

The ACS urges premenopausal women to get mammograms even though evidence suggests that premenopausal women are more sensitive to cancer risks from radiation: there is no evidence of benefit or effectiveness for premenopausal women; false negatives – as well as false positives – are common because the dense breast tissue of premenopausal women confounds test results. The NCI no longer endorses premenopausal mammography, nor is it practised in Canada or Europe or any other country in the world.⁵³

In addition to conflicts of interest and a one-sided focus on genetic research, the “cancer establishment” has also been accused of putting the responsibility of preventing cancer on individual lay people. Former NCI director, Samuel Border, acknowledged the importance of achieving the primary goal of cancer control through prevention, and that the best course was through the enhancement of individuals’ awareness via personal habits, behaviour and patterns of practice. However, in another article Epstein criticises the NCI for “trying to change lifestyles without in any way seeking to reduce unknown exposures to industrial carcinogens in air, water,

⁵² Samuel Epstein, “American Cancer Society: More Interested in Accumulating Health Than Saving Lives,” <http://www.wnho.net/acs.pdf>.

⁵³ *Ibid*, 38.

food, the home and the workplace”.⁵⁴ He also argues that focus on lifestyles and high-fat diets as the main cause of increased cancer incidence was overrated, or possibly nothing more than a strategy employed by the cancer establishments to blame the victims. As for advocating secondary prevention in the form of screening and using chemicals and vitamins to reduce cancer risk, Epstein contests that this simply shifts the focus to damage control rather than prevention.

Whether environmental factors are secondary, as Ames claims, or it is as Epstein states – that we are losing a winnable war against cancer due to run-away industrialisation and technology, particularly the petrochemical and radionuclear growth since the 1940s, which has outstripped the development of social control infrastructures and mechanisms⁵⁵ – cancer is a matter of politics.

So who is really participating in this cancer politics? And how? Perhaps ultimately, to take part in the politics of cancer means that the general public should consider cancer and its cause(s) in their everyday lives and constantly challenge the seemingly rational and objective authority of science. In other words, what Epstein’s politics inevitably brings about is activism in the public from the grassroots level, or, as Sharon Batt writes about the politics of breast cancer, “Advocating for ourselves means seeing our own interests clearly – no easy task when others have spoken for so long on our behalf... women with breast cancer began by asking why accurate information about the disease was so difficult to come by, and move on to examine how decisions are made and money is spent.”⁵⁶ That is to say, although environmental factors do not comprehensively explain, let alone stop cancer, their importance has encouraged various social and cultural efforts to place matters in the

⁵⁴ Samuel S. Epstein, “Winning the War Against Cancer?...Are They Even Fighting It?” *The Ecologist* (Vol. 28, No. 2, Mar/Apr 1998), p. 74.

⁵⁵ Samuel S. Epstein, “Reversing the Cancer Epidemic,” *Tikkun* (Vol. 17, No. 3, 2002), p. 57.

⁵⁶ Sharon Batt, *Patient No More: The Politics of Breast Cancer* (Melbourne: Spinifex Press Pty Ltd, 1994), pp. xxiii-xxiv.

hands of the public and encourage individuals to assert their right to investigate a disease. This has also given rise to a new culture of patient-driven cancer research. For example, *Rachel's Daughters* (1997) is a documentary film about a group of women who see themselves as the spiritual heirs of Rachel Carson because they also have breast cancer and act as detectives to investigate the cause of their cancer. The film was made by Allis Light and Irving Saraf in 1997, three decades after the publication of *Silent Spring* and subsequent to their then thirty-nine-year-old daughter's breast cancer diagnosis. Another example is Sandra Steingraber, whose own bladder cancer at the age of twenty showed that while it is more convincing if cancer can be traced back through the family genetics, her own case as an adopted child proved that there was more to her story. Later, in Steingraber's academic research and publications, she described an apparent "cancer cluster" in her hometown in Illinois, U.S. and wrote extensively on the environmental factors that could contribute to cancer and female reproductive health problems.⁵⁷

An increasing number of public interest groups are being established to force governments to improve the regulation of environmental and occupational carcinogens in the environment. For instance, another group of Rachel Carson's followers noticed that the very desire for precise, exact biological and molecular detail in intensive cancer research had actually restricted its scope, such that the bigger picture behind the minutiae was frequently forsaken.⁵⁸ The advocates of an ecological approach argue that specialised work in cancer research will eventually become an obstacle to the study of the whole that will drive us ever further from the goal of curing cancer until we are left with the scattered domains of specialists in

⁵⁷ For example, see Sandra Steingraber's "Exquisite Communion: The Body, Landscape, and Toxic Exposures," *Ecology and Design: Frameworks for Learning*. Ed. Bart R. Johnson and Kristina Hill (Washington D.C, Island Press, 2002), pp. 192-202.

⁵⁸ Zac Goldsmith, "Cancer: A Disease of Industrialisation," *The Ecologist* (Vol. 28, No. 2, March/April, 1998) p. 99.

various fields. There has been a movement away from biomedicine that has resulted in a growing body of popular literature on cancer and its vast array of environmental causes. Once released from the grasp of the sole determining factor of genetic heredity that has long signified professional elitism and knowledge mastery, we are now able to consider cancer from other, non-biomedical perspectives. Hence, it is the attempts of these mixed and contradictory voices to describe the amorphous nature of cancer that has turned our attention to cancer prevention.

These efforts to find an escape from cancer's doom have become another way of living with cancer that enables individuals to tell different stories of cancer by placing the disease within the frames of socio-politics and everyday life. Although Carson died of breast cancer eighteen months after the publication of *Silent Spring*, she initiated an unprecedented movement among cancer patients, their families, and caretakers to single out the environment as a cause of cancer. This movement also emphasised the importance of fighting for our own health, precisely because we are caught in our own versions of "the politics of cancer".

In conclusion, this chapter has looked at cancer's medical definition, its signs and symptoms, its cause and effect, and its numbers and statistics as part of what makes up the scientific narratives about cancer. I have argued that while we may learn what cancer is from the scientific/biomedical texts, it is also because of its inherent incoherence and inconsistency that we are able to catch a glimpse of the divisive and heterogeneous voices that also contribute to the other(ed) realities of cancer – those that are beyond the scientific realm. To put it differently, one way to make sense of the scientific knowledges of cancer (both embedded in what is said and what is expelled/displaced in the producing of scientific discourse) is to take it beyond the well-circumscribed biomedical space into other relevant realms such as

the environment, politics, personal lifestyle, different industries' vested interests, and the other factors that envelop the disease.

Chapter Two – The (Non)representation of Ghost and “Timearc” in Cancer

Narratives

Most stories are structured with a beginning, middle, and end. As I have shown in the previous chapter, science has tended to depict cancer as a linear progression of a story, such a framework restricts our knowledge of the disease to a single dimension – one in which the past always leads to the present and the present can be projected into the future. Thus, when we encounter a disease that cannot be reduced to a single cause-and-effect theory, one that even eludes the grasp of time, it can only be rendered a “mystery”. In this chapter I explore some alternatives to a linear temporal structure in telling the story of cancer. Using Dorothea Lynch and Eugene Richards’ *Exploding into Life*¹ as the main text in my analysis, I argue that cancer’s presence is not necessarily suppressed by the patient/writer in his narrative in an effort to move on with his life. Indeed, suppressing the presence of cancer in a narrative does not mean that an individual is well or healed. Throughout my analysis of *Exploding*, I argue that cancer is rendered “unseen” is a negative presence, and because it is not an absence, it can actually interact with the visible and what is positively present to tell a more complex story of cancer. Lynch was an American freelance writer who was first diagnosed with breast cancer at the age of thirty-four. At the time of her diagnosis, there was little information about the disease, especially accounts of the ways in which cancer and its subsequent medical treatments could affect a patient’s body and life. Lynch’s domestic partner, the documentary photographer Eugene Richards, agreed to document Lynch’s surgery, chemo- and radiotherapy, and overall cancer experience. As a result, the book is populated with black-and-white photos of not only images of Lynch’s pre- and post-surgery, but also other cancer patients with whom Lynch became acquainted at the hospital.

¹ Dorothea Lynch and Eugene Richards, *Exploding Into Life* (New York: Aperture Foundation, 1986).

Exploding is a work composed of both Richards' photographs and Lynch's text that reveals what cancer (both Lynch's and that of others) was like. In addition to allowing readers to see what was visible, such as the scar on Lynch's chest after her mastectomy or Lynch alone in the dim corridor of the hospital, Lynch also makes use of her own written text as a voice that describes what is not visible in the images in an effort to make sense of what is represented. As such, I argue that we must also consider what is "invisible" and "not-there" in the narrative to achieve an understanding of the cancer experience that goes beyond the linear progression of time.

When we direct our attention to what is present but invisible in the representation, *Exploding* is a good example of how the "ghostliness" of the cancer experience can tell us more about a story of cancer that complicates the much taken-for-granted linear progression of disease. First, ghosts arise from the past and are only visible to certain people with the ability to "see" or "feel" them. To these individuals, ghosts are *negative presences* – they are there despite being invisible. To understand how this works, imagine having an adventure in a haunted house during a thunderstorm and the old, broken roof is leaking. The rain comes in through every broken window. Suddenly, you hear a creak from the floorboard behind you. You shine your torch in the direction of the creepy sound and see, to your horror, that the floor is entirely wet from the rain with the exception of the place illuminated by your torch, which is an eerie island of dryness, as if an invisible object has been sitting there. Such ghostliness is characterised as completely invisible to the technologies of observation, specifically seeing and listening. When the past manifests in the present in the form of a ghost, we can only rely on the visible to detect it. In this sense, both past and present are on the same plane of reality. Both presences are crucial in revealing the complete picture, and from here we can begin

to examine to what extent this is a “constant negotiation” of what can be seen and what is repressed or, more importantly, whether it is the repressed returning in a different form.

I begin this exploration by looking at how illness narratives can help patients with chronic and degenerative illnesses make sense of their experiences by reintegrating them with their main, ongoing life narratives. I then suggest that due to the unique nature of cancer, these experiences should not be exclusively understood as a linear sequence of events with a past, a present, and a future along a timeline. Rather, I argue that the experiences should be integrated into what I call a “timearc”. A timearc frames each fragmented event that comprises the cancer experience. Together, these timearcs form a spiral without a linear expression. Rather than moving linearly in a single direction, the time within the timearcs in the time spiral shifts, flows, slips, and stalls as it spirals up and/or down. Timearcs, as I reveal later in this chapter, are useful in illuminating the presence of “ghosts” in Lynch’s cancer narrative. Drawing examples from both the texts and images in *Exploding*, this chapter shows that such “ghostly” encounters with what is “invisible” or “not-there” in a representation produce a sense of anxiety in the reader and *touch* those witnessing other people’s pain and suffering.

Chronicling Life and Illness

Why do we tell stories? By translating *knowing* into *telling*, narratives help us understand stories from other cultures, even when we do not have prior knowledge of them.² Narratives are also useful in that they can take many forms. Graeme Turner’s work, *Film as Social Practice*, even claims that “what is clear is that the world

² Hayden White, “The Value of Narrativity in the Representation of Reality,” *Critical Inquiry* (Vol. 7, No. 1, On Narrative, 1980) 6.

'comes to us' in the shape of stories".³ The fact that there are stories means that there is naturally more than one "code" for transmitting a shared reality across cultures. Do all diseases share the same storyness across the "kingdom of the ill"? A life narrative is the story of one's life story, and it should be read as a smooth, continuous, linear chronicle – even if it is interrupted or cut short by disease. This is because most diseases are exclusively understood as temporary disruptions of physical wellbeing. Once a disease is diagnosed by the physician and treated accordingly, continuity and order are expected to resume in our bodies and lives, sooner or later. Illness as an interruption in a life narrative does more than just stop the present from continuing on deterministically, it actually requires a new form of storyness to cement the ruptures created by the interruption. To ascribe new meaning to the illness experience, which has not been pre-scripted as part of the life narrative, the meaning must first and foremost reconnect with one's life history. In *Illness Narratives: Suffering, Healing and the Human Condition*, psychiatrist and anthropologist, Arthur Kleinman, remarked that illness is "the lived experience of monitoring bodily process" and involves "the appraisal of those processes as expectable, serious or requiring treatment".⁴ As such, before seeking medical intervention, an individual has already had to live with these changed bodily conditions and make her own judgments accordingly.

An illness should be understood as a personal, social, and cultural experience that involves making judgements, such as whether one should see the doctor about what treatment option to choose. The patient must also decide whether she can financially afford the treatment that is best for her and whether she can take care of herself independently. An illness presents patients with problems that concern their

³ Graeme Turner, *Film as Social Practice* (London and New York: Routledge, 1999) 78.

⁴ Arthur Kleinman, *The Illness Narratives: Suffering, Healing & the Human Condition* (Basic Books, 1988) p. 4.

everyday lives and the people within their social circles. The changes patients experience in their ill bodies are socially and culturally shaped, which places the judgement that it takes to categorise, explain, share, and even communicate them outside the realm of purely medical and rational scientific language. Kleinman further comments on the career of an illness in relation to the life history of a patient in the following way:

Chronic illness is more than the sum of the many particular events that occur in an illness career; it is a reciprocal relationship between particular instance and chronic course. The trajectory of chronic illness assimilates to a life course, contributing so intimately to the development of a particular life that illness becomes inseparable from life history.⁵

These “many particular events” that make up a chronic illness are intrusions that alter the trajectory of a life course as a whole, but to tell the story of a chronic illness, the story itself will not, and cannot be separated from the life story of the patient. Once the author incorporates the illness into his ongoing life narrative, it begins a process of self-reconstruction in which the story of the illness becomes a life story.⁶

Recounting a chronic illness creates the narrative of a disruption that not only concerns the physical well-being of the body, but also the on-going life narrative awaiting a renewed continuity through reintegration and reinvention after the illness. As a result, illness narratives serve two main functions. First, they give meaning to the consequent physical pain and suffering. The disease as lived by the patient adds a new layer that cannot be sufficiently described by medical discourse or scientific theory. Because the body loses its predictability, this lived experience is a constant reinvestment of meaning in the patient’s original ongoing life narrative in order to, as Arthur Frank noted, restore the order that the interruption fragmented.⁷ Second, and more importantly, putting the experience into language gives the patient a

⁵ *Ibid.* 8.

⁶ G. Thomas Couser, *Recovering Bodies: Illness, Disability, and Life Writing* (Madison: Wisconsin, The University of Wisconsin Press, 1997) p. 44.

⁷ Arthur Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago and London: The University of Chicago Press, 1995) 60.

chronological perspective of her life. This shows that an illness narrative is specifically focused on managing the “now”. The patient can simultaneously acknowledge the fact that the interruption of his illness will continue as his questions about dying are successfully diverted. Therefore, it becomes a strategic tool for patients to displace their ontological crises. The narration of a chronic illness eases the patient back into the main course of her life by historicising each event in the course, such that they can be realigned to form a fragmented whole that allows a future to be projected. The product of an illness narrative, therefore, brings together two separately ongoing stories – the original about the patient’s life and the other about the illness – along the progression of the linear timeline. Patients compose illness narratives so that they can put things where they belong in the past with the goal of constructing a foreseeable future. Once new meanings are found, such narratives also help a patient establish a distance between his illness experience and the present moment in which he is situated, which produces a therapeutic effect. This effect is therapeutic because the act of rearranging events allows the patient to feel that she can finally put things in the past. Regarding the inherent creativity involved in arranging events within a story to explain how things happened, Gilberto Perez writes:

A narrative sequence, what is told first and what next and what next up to the end, is always to some extent an order of our making. The succession we make of things when we tell about them marks the artefact that is a narrative. A narrative is not just a story, something that happened or is imagined to have happened, but a story told: not a sequence that happened but a sequence made.⁸

⁸ Gilberto Perez, *The Material Ghost: Films and Their Medium* (Baltimore and London: The Johns Hopkins University Press, 1998) p. 51.

A narrative sequence allows the narrator to arrange how things happened by reinscribing each event with a new meaning during the process, which suggests a complex relation between the notion of time and the act of chronicling an illness.

Life-Threatening Illness and its Relation to Time

Our conventional understanding of time is that it is immensely and limitlessly expanding into the future. Therefore, time is commonly imagined as a promise of hope and certainty. The phrase “time heals” is an example of how common it is for people to believe that things look brighter and better in the future. Such optimistic imagination also corresponds to the way we imagine the “road of life”, where disease is treated as a mere “bump” that we must circumvent before continuing on the bright, straight road that stretches out ahead, on which our circumstances are expected to transform “down the road”. When a serious illness such as cancer shatters a person’s belief in a simple, mechanical explanation of disease to the extent that his ability to visualise the road of life is affected by the way he projects himself into the future, it makes him aware of his own mortality. Specifically, a patient’s association with time and the journey of life is warped when she is ill with a disease like cancer. When told by a doctor that they have cancer, people naturally wonder how much time they have left. Patients describe the moment they heard they had cancer or another life-threatening disease as “heart-stopping”, which alludes to the sensation that the timeline has come to an abrupt stop and the future has suddenly disappeared.

As I have mentioned, illness narratives depend on the arrangement of a narrative sequence that allows the narrator to make sense of what is happening in the face of a life-threatening illness. One way this can be achieved is by pathologising one’s past. According to Zygmunt Bauman, modern life is characterised by “the conceptual pathologisation of daily life”. This means that in response to our

awareness of our own mortality, what we used to perceive as life's finer states of subtlety and sophistication become the result of uncontrolled passion or the "prospectless void of ennui", which results in the radical medicalisation of "most private or collective worries". Thus, our fear of the ultimate end appears more manageable because the "causes" of our imminent end can now be treated. Citing alcohol consumption as an example, Bauman argued that what used to be considered vice is redefined as illness, and immorality as pathology:

Scratch any 'social problem', any 'personal misfortune', and a *pathology* will be revealed which calls for some medical action – surgery, regime, drug prescription, hospital-style supervised confinement. Behind the bane of the inner cities – vagrancy and begging – there was the neurasthenic condition; behind striking workers there was mob psychosis making its victims susceptible to the incendiary exhortations of the demagogues; there were specific, ubiquitous pathology in the 'normal' life conditions of the hyper-active and hyper-tense bourgeois buffeted by the cross-waves of competitive pressures, of the dissipated and idle offspring of privileged, affluent families, of middle-class women debilitated by the lack of function to the point of sexually rooted hysteria.⁹

People who drink obsessively are now called alcoholics and require counselling and treatment while tobacco smokers are often seen as people who are irresponsible about their own health because smoking is now equivalent to committing a slow suicide. No matter how many names we create for our bad habits and the other risks that give us pleasure, Bauman added that such efforts (preoccupations with health and fighting diseases) barely veil the finite truth of mortality.¹⁰

Pathologising the past requires that we mentally assign blame for our disease in the present. This is then followed by the need to plot the narrative in such a way that the past can be redeemed and a future can be visualised. The concept of "therapeutic emplotment", as developed by Del Vecchio Good et al., is useful here for understanding how this can be achieved. Therapeutic emplotment is defined as "the

⁹ Zygmunt Bauman, *Mortality, Immortality and Other Life Strategies* (Cambridge, UK: Polity Press, 1992) p. 148.

¹⁰ *Ibid.*, p. 149.

interpretive activity, present in clinical encounters, through which clinicians and patients create and negotiate a plot structure within clinical time, one which places therapeutic actions within a larger therapeutic story".¹¹ It emphasises the restructuring of time in clinical encounters to help recontain a patient's fear of their own mortality, which instils hope even during the arduous process of treatment. In addition, by reorganising time in more manageable, day-to-day units, patients are encouraged to live in the "immediacy of treatment" and believe that completion of the treatment will mean that "some kind of certainty might be reached".¹² This has two distinct advantages. First, it creates a new perspective regarding the patient's past. For example, if the patient subscribes to a new health regime after her illness, she is more likely to look at her past as it existed before her illness from a different perspective. The past is thus redeemed. Second, it can reorient the patient so that they are facing the future more positively. However, such emplotment is viable only on the condition that the patient's clinical and subjective time experiences are in sync. This also means that the narrative is plotted not according to the progress of the illness, but according to the treatment. In other words, it is only through a plot that features the absence of the illness that the ontological crisis can be contained.

Cancer and Timearcs

Cancer is a different kind of serious illness in which the patient's chronological time and his personal, subjective time are dissociated. Despite the fact that the force of time can still be imagined as capable of overcoming the aforementioned "bumps in the road", a patient's sense of how time passes is irreversibly disrupted, such that the vast container for all sorts of possibilities and

¹¹ B.J. Good and M.J. Del Vecchio Good, "In the Subjunctive Mode: Epilepsy Narratives in Turkey" *Social Science and Medicine* (Vol. 38. No. 6, 1994), p. 855.

¹² Michele L. Crossley, "'Let me Explain': Narrative Emplotment and One Patient's Experience of Oral Cancer," *Social Science & Medicine* (Vol. 56, No. 3, 2003) p. 444.

options located in the future shrinks considerably. To complicate things even further, cancer patients do not necessarily experience time in a linear way, and this experience is not exclusive to cancer patients. For example, according to T. Jock Murray, people who are suffering from multiple sclerosis experience time differently at a very personal level:

Patients generally have variable perceptions of how time moves, depending on the circumstances and the illness. A painful procedure can seem to last longer, but apprehension of a coming event that they dread can make time seem to move too fast.¹³

For these patients, time is no longer strictly linear, to the extent that some people may even experience a circular motion of time based on the repetitive nature of the disease, which requires that they readjust after each attack. As Murray observes: “once [the patient] has adapted to a new level and way of life, the next attack leaves further deficit, demanding a new adjustment.”¹⁴ In this sense, the triangular relationship between patient, time, and illness shifts and what used to be woven into a straight line leading into the future is cut short, such that the patient is left to his own devices to make it “foreseeable” again by bending the timeline into a circle. Most notably, time is then broken into one cycle after another, as Murray described: “the regularity of the rising sun, the changing light in the day, the appearance of hospital staff, the lengthening shadows of the day, lights out, sleep, only to awake to the new light, the arrival of cheerful staff ...”¹⁵ Time is marked by small, recurring events that were previously ignored in healthier times, such as getting out of bed, brushing one’s teeth or stepping out of the house. Unlike multiple sclerosis, however, cancer does not usually leave patients with permanent physical damage or the inability to resume their bodies’ normal functions. In fact, cancer’s remission stage is proof that cancer

¹³ T. Jock Murray, “Personal Time: The Patient’s Experience,” *Annals of Internal Medicine* (Vol. 132, No. 1, 4 January 2000), p. 58.

¹⁴ *Ibid.*

¹⁵ *Ibid.*

patients are not living on the typical timeline known by people suffering from chronic or degenerative illnesses. First, cancer cannot simply be characterised by the usual illness trajectory of symptoms, diagnosis, treatment, and cure/management. Cancer is not the story of physical deterioration over time or the fight against a “foreign invasion” using biomedical advances. Due to the lack of a distinctive state to define the progression of cancer, the past, present, and future all collide on the same plane, emanating from one central point that is eternally regressive. This can be best summarised by Stacey’s remarks on the ambiguous status of cancer patients, specifically the fact that there is no appropriate tense or grammar for the narrative of cancer.¹⁶

People living with cancer are not simply living in a circular, repetitive timeline, but in various *timearcs*. These *timearcs* do not follow any specific direction, action, or pattern. In other words, there is no standard perspective of the passage of time. For example, for most cancer patients, experiencing remission for the first time is encouraging. It can even be viewed as a heroic victory. When it is happening for the second or even third time, however, the initial euphoria is often replaced by distress and fear as the cancer reality begins to sink in once again. Repetition, in this case, is the result of a progression through time that is also a kind of regression of the patient’s subjective time. If time “flows” or “flies” or “passes” on the timeline, then it “spirals”, “slips”, or even “suspends” on *timearcs*. Moreover, cancer’s temporal structure, despite its seemingly repetitive pattern, actually spirals (downward) with each (random) piece of an arc taken from the spiral not overlapping the pieces before or after. In this sense, the previous event may not necessarily lead to the next one (such as a lump in the breast can be a false alarm). Such a structure allows each layer of the spiral to contain a *timearc* that frames one specific cancer event, similar to a

¹⁶ Jackie Stacey, *Teratologies: A Cultural Study of Cancer* (Routledge: 1997), p. 7.

snapshot of an illness world, but the “progression” of these events does not necessarily indicate movement towards a certain point on the conventional timeline.

Understanding the cancer experience as framed by these timearcs also helps explain why cancer narratives cannot tell the shared stories of a collective past, unlike in a normal timeline along which events can coincide (as in the case of a coincidence). In fact, even for two people with the same cancer, the distances and differences between their two sets of spirals ensure that the destiny of either party remains forever unknown and unexplored. This is evident in Jackie Stacey’s brief dialogue with a stranger she met in Crete while on vacation, who was also suffering from the very same, rare cancer as Stacey:

A teratoma? So was mine. You had it removed, and an ovary too? So did I. And chemotherapy? Bleomycin, etoposide and cisplatinum. Me too. I’ve got these strange scratch marks on my skin as a side-effect. So have I. I have having AFD tests every week. So am I. My tests are clear so far. So are mine. I’ve been taking high doses of vitamins. So have I. I’ve tried all the alternative medicines. So have I.¹⁷

Naturally, having the same type of cancer probably entails the same treatment will be prescribed and undergoing the same treatment implies using the same drugs and perhaps ending up with the same prognosis, but as the above passage show, the dialogue between the two patients does not tell a story of cancer because these coincidences cannot be extended to the additional series of events that are also connected by a common temporal sequence. In the end, Stacey and the other patient parted as strangers without sharing anything more about the past, let alone the future.¹⁸ Calling the stranger Stacey’s double not just because of the similar physical appearance due to cancer but also because of shared history between the two, Lisa Diedrich further remarks that “The gap that opens up between their stories reveals the

¹⁷ *Ibid.*, p. 19.

¹⁸ Lisa Diedrich, “A Bioethics of Failure,” *Ethics of the Body: Postconventional Challenges*, ed. Margrit Shildrick and Roxanne Mykituk (Cambridge, Mass: MIT Press, 2005) 139.

impossibility of shared histories, and it reminds Stacey that uncertainty and contingency are all that she and her double really share”.¹⁹ What cannot be shared while their stories converge is precisely what dis/appears into the spirals, within which each *timearc* (that frames each event/incidence) does not actually intersect with the same point on the timeline. This can also explain why the initial recognition can only turn to what Diedrich calls an inevitable “future misrecognition”. This dis/appearance, according to cultural critic Ackbar Abbas, does not mean nonappearance or absence, but rather a pathology of presence due to misrecognition.²⁰ To misrecognise something, one must have had a prior encounter or knowledge of it. With this understanding, cancer, as it appears in any representation – including visual portrayals in forms such as paintings or photographs or illness narratives written by patients – is often a misrecognition. It is either a progression into an abstraction of signs and images of the former, fragmented events locked in one time (or space, for the latter). In Stacey’s example, they are simply relegated to names, clinical encounters, and information-sharing. This kind of sharing should not be misrecognised as storytelling, either. As Frank noted, storytelling should be a communicative act through which a patient reclaims her voice. Because seriously ill people are not only wounded in body, but also in voice, the act of telling stories serves to recover what the illness and its treatment have taken away. Thus, Frank believed that just because someone is suffering, does not mean that they are confined to the passive, sick role, but that they actually have something to “give” and “teach”.²¹ According to Frank, the term “emphatic bond” describes the bond between two communicative bodies created through storytelling, when “a person ‘is

¹⁹ *Ibid.*

²⁰ Ackbar Abbas, *Hong Kong: Culture and the Politics of Disappearance*, (Hong Kong: University of Hong Kong Press, 1997), pp. 7-8.

²¹ Frank, *The Wounded Storyteller*, p. 150.

with' another: a relationship in which each understands herself as requiring completion by the other".²² However, in the verbal exchange quoted above, the level of intimacy that the dialogue enabled is as far as a mirrored image can go and as the moment passes, a different reality/realisation settles in:

I wanted to say, 'Tell me everything and tell me now. Here on the doorstep.' I could hardly bear the suspense. I was torn between a desire to stay forever and to compare all the details of our stories, and my sense that we had only just met ... Having had cancer is no guarantee of friendship.²³

The Unspeakable – The “Ghost” of Cancer

Understanding cancer from the perspective of a temporal structure such as the timearc reveals what cannot be shared between two people or even among other people living with cancer. To a certain extent, we can say that timearcs even allow us to have a glimpse of the collective experience of cancer as witnessed through the “unspeakable”. It also means that there are other ways to tell the story of cancer beyond the traditional linear narrative. The notion of a timearc frees cancer from the conventional diagnosis-treatment-prognosis trajectory and creates a narrative space, which is made up of both timearcs and the gaps in between each layer of the time spiral, to include what cannot be spoken. Although cancer does not necessarily mean death, it is not surprising to find that death (and dying) is what is consciously avoided. Similar to most illness narratives, there is no proper way to incorporate the possibility of dying in cancer narratives because most of them are “therapeutic” in that they focus on immediacy and hope along with the day-to-day personal struggle and progress. However, this does not mean that the feelings of uncertainty, fear, and anxiety can be completely masked as a result. These are what I call the “ghosts” in the cancer story.

²² *Ibid.*

²³ Stacey, *Teratologies*, p. 19.

To make sense of pain and suffering, narratives require the author to speak from the present, thus leaving questions about life and death subdued for the sake of asserting other small victories in everyday life. Thus, the idea of “ghosts” is an effective metaphor for what cannot be represented. As Stacey explained, the function of metaphors in writing about cancer is to set up a buffer between us and the unspeakable so that we can continue with our everyday lives:

Fear produces a desire to avoid and deny and most particularly to transform. The fear which the naming of cancer engenders fuels the desire to seek linguistic reassurance: perhaps cancer does not have to be confronted if we do not speak its name. Metaphors rush to the rescue of the subject whose terror is otherwise uncontainable.²⁴

Stacey’s observation shows that the use of this particular linguistic ornament also serves the purpose of illuminating the unspeakable or unrepresentable aspects of the experience. As a result, questions of death and dying, albeit an important part of the cancer experience, become immaterial and even antagonistic until finally, they become traces of shadows behind more scientifically and medically neutral terms such as “remission”, “recurrence”, or “statistics”. Metaphors shield us from the trauma caused by intense fear because they help us integrate what is unspeakable back into our imagination and even our language. In this regard, metaphors are actually the “traces” of materialisation on the other side of the cancer reality that is shrouded in dark shadows.

The use of metaphor also directs our attention to the possibility that the muffled silences and exclusions, or what sociologist Avery Gordon described as the “smeared print, ghost images” in a text might be portrayed:

To write stories concerning exclusions and invisibilities is to write ghost stories. To write ghost stories implies that ghosts are real, that is to say, that they produce material effects. To impute a kind of a kind of objectivity to ghosts implies that, from certain standpoints, the dialectics of visibility and

²⁴ Stacey, *Teratologies*, p. 63.

invisibility involve constant negotiation between what can be seen and what is in the shadow.²⁵

Gordon uses a “ghostly matters” category to argue that what is invisible is not necessarily not-there and that the purpose of writing ghost stories is precisely to investigate how what appears as absent can actually be a “seething presence”.²⁶ We can also use these “ghostly matters” to explain why it is worth exploring the “ghost stories” embedded in a cancer narrative and reveal how they co-constitute the cancer reality. To do this, we must imagine each event as being represented by a timearc, because while timearcs comprise the cancer experience, each individual piece of each timearc does not suggest any causal relations to other events. In other words, the pieces are not arranged in such a way that one event can foretell or explain another. Therefore, one must consider “what is not there” to grasp the entire experience as a simultaneity. This can be imagined as things caught in the empty spaces between each timearc as they oscillate and gyrate in the time spiral. Specifically, these are the “not-there” elements that have never been properly registered at any specific point in time. For instance, the diagnosis process may take weeks, but at what point does the person become a cancer patient or a person living with cancer?

Making sense of what is not there is a kind of “ghostly encounter”. In fact, the likening of a bodily experience to a ghostly encounter is nothing new. Consider the occurrence of phantom-limb pain for insight. As a common sequela of amputation, up to 80% of people who have undergone the procedure will feel the sensation that the deafferented body part is still present.²⁷ The determinant factors are believed to be the spinal mechanism and the nociceptive input from the residual

²⁵ Avery Gordon, *Ghostly Matters: Haunting and the Sociological Imagination* (Minneapolis: University of Minnesota Press, 2008) p. 17.

²⁶ Gordon developed this from the concept of “hysterical blindness”, a term coined by Laura Kipnis to mean that something that is highly visible can actually take on a type of invisibility. Gordon reverses the argument to suggest that something that is invisible is not actually “not-there”.

²⁷ See Herta Flor’s “Phantom-limb pain: Characteristics, Causes, and Treatment” *The Lancet Neurology* (Vol 1, July 2002) pp. 182-189.

limb, but most notably the phenomenon is elicited by pain memories that are established before the amputation.²⁸ Nonetheless, whether it is a ghostly encounter with cancer or a phantom pain, to the person who is experiencing it, it takes on a very real material/sensual presence no matter how hard he tries to deny or even suppress it. This is also where biomedicine stumbles. There is no cure for or prevention against pain generated by memories and these small, daily struggles simply cannot be translated into codes to be decoded later into repeatable scientific experiments. A cancer patient does not necessarily feel the tumour growing inside her body until it affects other organs or manifests itself visually (e.g. haemorrhage and weight loss). Perhaps more importantly, like every ghost, cancer arises from a past that haunts the present to remind the patient of a “suspicious” pain or “strange” swelling at one point in time. When we look back, however, we only see how time has made its menacing mark about the past in the present. The actual past has no material place in the world anymore because the cancer has been removed. Thus, when the disease’s ghost returns to haunt us, our language is doomed to fail in its representation.

As a story, cancer cannot simply be traced back to a moment in the past and then narrated up to the present so that a future can be projected. As a disease, it is not a biological reality because cancer, far from being a “natural” object that can be studied under the biomedical lens, is what Stacey referred to as a (cultural) phenomenon that haunts the imagination along its trail of presence/absence. It is commonly believed that as long as the tumour is removed, the patient is already on his way to “healing”, but throughout this healing process, is he merely dealing with the prospect of health itself? What if his other senses are registering “chilling creeps” about *other* invisible presences? How can language help him cope?

²⁸ *Ibid.* p. 186.

The "Ghostly" Story: *Exploding Into Life*

There are quite a number of outspoken and visual cancer narratives that aim to show readers what having cancer is like. These well-known narratives in cultural studies are mainly concerned with breast cancer and the female body, probably because the treatment of breast cancer involves a form of mutilation that not only disfigures the body itself, but also the patient's femininity. The autobiographical writings and photography of female poets/artists such as Audre Lorde, Jo Spence, and Matuschka focused on how a body marked by cancer and/or a missing breast challenges the codes of representation and cultural ideologies of the female body.²⁹ By arguing that a woman's body is socially constructed, bodies ravaged by illness that were once silenced are given voice. In this sense, creative works about (breast) cancer allow a patient to make use of her ill body and its representations to reject the socially negative labels that come with the disease and express agency in interpreting her own illness. However, these stories behind the representation of a missing breast are actually based on what is *still there*, such as the representation of a body with the remaining breast. These stories are about what *can* be seen, but is it possible to have a cancer narrative that tells more than it shows? Specifically, is it possible to have a narrative that foregrounds what is *not there*? *Exploding into Life*, the testament of a woman confronting her own breast cancer at the age of thirty-four, is an interesting case in point. With its black-and-white photography and written text in the form of a diary, the book offers a different perspective on how a cancer experience can be narrated. Rather than telling a cancer story based on the traditional linear flow of time and sequencing of events, Dorothea Lynch's text, coupled with her partner's photography, reveal how cancer can be present despite its invisibility and, as I

²⁹ See Audre Lorde's *The Cancer Journals* (San Francisco: Spinsters Ink, 1980); Jo Spence's *Putting Myself In The Picture: A Political, Personal, and Photographic Photography* (London: Camden Press, 1986); and Matuschka and Anthony Haden-Guest's *Bagit!* (New York: Hard Press, 2008).

discuss in the next section, how it is through this presence of the *not-there* that a collective experience can be witnessed.

The book begins with Lynch's diagnosis of breast cancer. After consulting with the doctor, she is forced to choose between the only two treatments available – radiation or mastectomy. The doctor encourages her to look at these options carefully, but Lynch soon concludes that there is not much to look at:

I try to find out what a mastectomy looks like so I call the American Cancer Society. The woman on the other end tells me that books with pictures of cancer treatments aren't considered suitable for non-medical people. Volunteers at the National Cancer Institute and Cancer Information Service refuse to discuss primary radiation or other alternatives to surgery, instead counselling me to have a mastectomy, the 'proven method of treatment.'³⁰

As a journalist, Lynch's original intention is to publicise the plight of cancer patients in photographic form, but not in testimonial-style pictures that merely supplement the written narrative. To achieve this, she has her domestic partner, Eugene Richards – a documentary photographer – visually record the ups-and-downs of her physical and emotional changes.

As previously discussed, writing about one's cancer experience can be considered therapeutic because it addresses the need to remember and reconstruct the experience, which is essential to the healing process. More than just a therapeutic experience for Lynch, *Exploding* also doubles as a documentary of other people's cancer experiences because rather than simply re-arranging a sequence of events to tell her own story, she injects all of the recorded events with the simultaneity of the present moment in through photography and the voices of others. Prevalent throughout *Exploding* is a strong sense of obligation to reveal pain and share and unveil the sick, suffering body without deliberately minimising interactions with

³⁰ Dorothea Lynch and Eugene Richards, *Exploding into Life* (New York: Aperture Foundation, 1986) 16.

doctors and medical authorities. Since it does not render the images artistic, it is actually one of the few cancer narratives in which the readers are presented with candid images of what it is like, for example, to be on the operating table and, later, to recover in a hospital bed. Here, the “ghostly images” of cancer are definitely not in “the spirit of the dead” (a past whose meaning is dead), but rather should be taken as the traces left behind in the struggle between forgetting and remembering. The paradoxical need to simultaneously forget and remember was described by Stacey in the following way:

I have also needed to reflect upon my own psychic desire to write about the subject: perhaps this has helped me to externalise the experience, place it as firmly in the past as possible, and even (despite my own cautions) to enjoy a fantasy of regained control. Or perhaps it has enabled me to “forget” in some sense. For remembrance itself can also be a form of forgetting. These interpretations point towards the idea of writing as restoration and, indeed, there are those who have celebrated the idea that writing can somehow heal the wounds of life.³¹

To clarify my point about forgetting and remembering, I find it useful to relate the cancer experience to that of a traumatic event. According to Cathy Caruth, a traumatic event includes a period of latency during which the effects of the experience are not apparent and the trauma itself can only be initially experienced in and through its inherent forgetting. Caruth notes that this is also what puts a traumatic experience within a temporal structure of belatedness because “the traumatic event is not experienced as it occurs, it is fully evident only in connection with another place, and in another time”.³² In the event of cancer, this by no means refers exclusively to a future time or space. If we think of time as travelling downward in a spiral, what is “ahead” has actually already been contained by the wider arcs in the “past”. This is a different form of the sheer repetition of time because it is without any causal relation between *this* and *other* time and space. If

³¹ Stacey, *Teratologies*, p. 23.

³² Cathy Caruth, *Trauma: Explorations in Memory* (Baltimore and London: The Johns Hopkins University Press, 1995) p. 8.

Exploding is to offer us a new mode of narrative for the cancer experience, then this new mode must first deal with the problem of situating cancer within its own dis/appearance to develop a technique that responds without historicising what is happening between forgetting and remembering. Similar to that of traumatic memory, it is a storyness that represents a “ghostly presence”.

The presence of ghosts in storytelling does not necessarily constitute “horror literature”. In her analysis of the way ghosts appear in African-American literature and how they are used to enhance the development of the (female) characters in novels, Gail Sidonie Sobat cites Carl Jung to argue that ghosts form a bridge between one’s conscious and unconscious, particularly if memories or pain have been repressed. The creation of an apparition or poltergeist in a fictional text is an attempt by the psyche to ease its burden through the process of memory.³³ However, the ghosts in cancer narratives are not, and cannot, be easily described. It is up to the reader to acknowledge what is in the shadows. The narrative and images in *Exploding* form a counteractive force of time in which each moment that passes does not mean that things are left in the past and hence fixed or “dead”, but rather they actively validate each other and move along the timearc in such a way that the present can still linger even when it is abruptly discontinued. For example, at times, when Lynch becomes too sick to write, her partner can help her keep the documentation going by taking a picture that shows her sitting on the floor in front of the toilet with tears in her eyes – one hand curled in a fist, exhausted from vomiting (see Figure 1).

³³ Gail Sidonie Sobat, “If the Ghost Be There, Then Am I Crazy?: An Examination of Ghosts in Virginia Hamilton’s *Sweet Whispers*, *Brother Rush*, and Toni Morrison’s *Beloved*,” *Children’s Literature Association Quarterly* (Vol. 20, No. 4, 1995) p. 169.



(Figure 1)³⁴

Even though the “now” is discontinued from the written narrative, its “spirit” continues through the instant image, which makes up for its absence from the text. The “now” is a presence that is deprived of a voice or a direct reference because it is implied in Lynch’s expression, body language, and the way in which the image is framed. Silent and still, it is a moment of embodied remembrance in which what has not been said is not forgotten and is, by no means, an absence.

Theories of traumatic experience also tell us that it is the kind of experience that fails to speak to us at the first instance, such that the “ghostly voices” that come to haunt us cannot be consciously heard. If we refer to Caruth again, her reading of Freud illustrates that it takes more than one voice to talk about the ghostly story of cancer. Freud begins his analysis of trauma by describing a story told by Tasso in his romantic epic *Gerusalemme Liberata*, in which the hero, Tancred, has unknowingly killed his beloved wife in a war. That was not the end to the tragedy, however, and his fatal act is re-enacted later when he makes his way into a strange, magic forest where his wife’s voice cries out from a tree, which he slashes with his sword.³⁵

Caruth uses this story to suggest that there is more to a traumatic experience than the

³⁴ Lynch and Richards, *Exploding*, pp. 52-3

³⁵ Originally described in the third chapter of *Beyond the Pleasure Principle*, Freud used this story to illustrate a fate that seems like a possession by a series of painful events that are out of the individual’s wish or control. The original story is cited in Caruth’s *Unclaimed Experience: Trauma, Narrative, and History* (Baltimore: The Johns Hopkins University Press, 1996) 2.

unconscious act of inflicting the wound and the subsequent compulsory repetition of the event. As Caruth notes, based on what happened to Tancred, there is also “the moving and sorrowful voice that cries out, a voice that is paradoxically released through the wound”.³⁶ Although cancer patients do not necessarily suffer from compulsory repetitive nightmares of the cancer experience, it is strikingly similar to a traumatic event because it is not, as Caruth so aptly remarks:

locatable in the simple violent or original event in the individual’s past, but rather in the way that its very unassimilated nature – the way it was precisely not known in the first instance – returns to haunt the survivor later on.³⁷

Unlike physical violence or a catastrophic event, which involve the infliction of a physical impact (or wound) on a person’s psyche, the trauma caused by cancer does not have any referential force. In fact, the “trauma” of a cancer experience means different things to different patients. Most noticeably, it was the surgery that was the most unthinkable before anaesthetics were invented. For example, when Fanny Burney wrote about her mastectomy experience in the early 1800s, the nightmare for her lay not in the impact of cancer “happening” to her, but in what followed the diagnosis. In her letters to her sister, Burney detailed what was being done to her body during surgery, including the pain and fear she felt:

When the dreadful steel was plunged into the breast – cutting through veins – arteries – flesh – nerves – I needed no injunctions not to restrain my cries ... When the wound was made, & the instrument was withdrawn, the pain seemed undiminished, for the air that suddenly rushed into those delicate parts felt like a mass of minute but sharp & forked poniards, that were tearing the edges of the wound ... I then felt the Knife <rack>ling against the breast bone – scraping it! – This performed, while I yet remained in utterly speechless torture ...³⁸

³⁶ *Ibid.*

³⁷ *Ibid.*, p. 4.

³⁸ Fanny Burney, “Mastectomy,” *The Journals and Letters of Fanny Burney (Madame D’Arblay)* (Oxford: Clarendon Press, 1972-1984, Vol. 6) 600.

The present-day use of anaesthetics spares patients the pain and intense fear of having their body cut open while they are still conscious.³⁹ As a result, writing about the post-surgical experience requires a reformulation of the pain and, more importantly, the reactivation and rearticulation of the related memories so that the wounded body opens up a new field of signification for the suffering one faces during treatment.

Despite the differences in traumatic impact during or after surgery, cancer shares the same unassimilated nature with traumatic experience. The unknown in the first instance is never registered in the person's consciousness, yet unlike a traumatic experience, the "trauma" of cancer is a return of the unknown as "known" to haunt the "survivor" – things once familiar to the patient from her past. The "ghostly voices" masquerade in the form of easily recognised and readable signs. For instance, a headache can be read as a "sign" of recurrence. The same is true for a stomach ache or a general feeling of fatigue. These signs constantly repeat in various forms to remind the patient of what is already known. When we are hyper-sensitised to these appearances and reappearances in the forms of apparitions, it is no longer significant whether they are merely hysteria, misrecognition, or the real, material influence of a ghostly presence in the body.

Ghosts and Collective Suffering

The double-stranded narrative in *Exploding* also enables the collective witnessing of a cancer experience. As such, *Exploding* locks cancer in the present using this double-stranded narrative and, like the double helix of DNA, the narrative strands depend on one another to form messages and information. Lynch's initial response and the opening of her narrative – "I was stunned," followed immediately by

³⁹ According to her journal, Burney was only given a "wine cordial" which produced "a kind of stupor prescribed as an anaesthesia." See *ibid*, p. 610, n. 30.

a close-up of her crying – reveals the collaborative nature of the endeavour, the goal of which is to validate the patient's fear and sadness as a natural emotional response to cancer, although this sentiment is not further illustrated through Lynch's words. By combining the medical and personal cancer realities in this joint effort, it becomes clear that the images are constantly trying to catch up to the progression of what these two realities bring forth, which exposes the struggle between remembering and forgetting and between the personal and the collective. Moreover, the double-stranded narrative is able to relate to the concept of a timearc that characterises the cancer experience. Images of personal suffering are different from images of physical suffering, or the images of dead bodies presented by the media. The disaster images that we have grown accustomed to in news footage are more or less direct quotes from reality, and if they are not real, then they are fictions depicted on screen. We see what the directors or photographers want us to see, through their lens: injuries are visible to the observers' eyes, the dead lay still, and the cameras are not trained directly on the faces of the suffering or deceased unless the image is a depiction played by an actor. These are the things that we expect to see when someone is injured or dead on-screen. They are mediated images presented with the intention of showing the viewers what they are suffering from, e.g., bleeding faces, broken limbs, lying unconscious with eyes half-closed. Such images are usually rendered emphatic via the use of close-up shots and they are mediated through an arrangement that ensures that they become removed from our everyday lives. However, we are also aware of the fact that we have the choice to turn away if such images become too much to look at or, as Alan Radley explains in "Portrayals of Suffering":

We look and are horrified; we turn away and the image, and the feeling, are gone. This does not mean that photographic images are altogether forgettable. What is forgettable is an image that is presentationally inarticulate, or one that through lack of narrative

commentary condemns it to the condition of being an instance, locked in time and space.⁴⁰

Dorothea Lynch's post-mastectomy photographs do not give her viewers/readers a direct opening into her world of suffering. The raw, unmediated form of photography in *Exploding* is what Radley refers to as a "stark presentation of the mundane world" from which the viewer cannot turn away precisely because it is a part of everyday life. Because such unmediated images do not directly emphasise what the subject is suffering from (unlike the visible bleeding and depictions of the body from the inside-out found in mediated images), they are more difficult to look at. Although what we see (e.g., a crying face) helps us make sense of what is happening, it is what we cannot see (e.g., what is in the toilet bowl, the sound of retching, the smell of vomit) that engages the embodiment of the observer through reactions such as horror, disgust, or sadness. We as viewers can only respond with a shudder – a bodily gesture intended to physically shake what we see from our minds – because unlike images that are "locked in an instance of time and space", these difficult images articulate suffering that permeates the mundane world that we all share. What we cannot see is being articulated and formulated by the surrounding elements. We are thus made aware of what Gordon calls the glaring "seething presence" of the invisible. In other words, it is the "invisible" that communicates and makes it possible to comprehend the illness world.

Radley remarks that not only do these images of the non-visuals (or the negative presence) restore the voice of the patients, but also both the artist and the observer's capacity to feel. In this way, we can even say that an illness experience can be witnessed (or felt) collectively. Such collective witnessing has a two-fold nature. First, we must remember that there are two narrative strands that run through

⁴⁰ Alan Radley, "Portrayals of Suffering: On Looking Away, Looking At, and the Comprehension of Illness Experience," *Body and Society* (Vol 8, No. 3, 2002), p. 6.

Exploding, and while Lynch is the subject under Richards' camera, she is neither anonymous, nor is her scar glamorised as a shocking spectacle. She is not objectified under Richards' gaze. Moreover, the images are accompanied by her own words, which she uses to describe her reaction to the difficulties she must face. At other times, as Couser noted, the images "fill the gaps in the narrative by depicting experiences that elude verbal representation".⁴¹ Nonetheless, while Lynch's narrative asserts control over her body, her experience is still witnessed and documented through Richards' eyes, such that they are responsible for portraying the other side of the cancer reality that lies beyond words. To render the viewer a witness rather than a spectator looking at a piece of art or watching a documentary, the images must first and foremost turn our attention away from photography as a medium to what we witness. Only then can we make sense of what is presented as a duet of the visible and the invisible; the muted, and what is spoken. This dichotomy is invoked through Lynch's portrayal of other cancer patients in the hospital, one of whom was Clistee Boles, whose daily habit involved watching soap operas "every afternoon from 1 to 4". Lynch must initially "struggle to communicate" with Mrs Boles, but slowly, "words and phrases, finally whole paragraphs begin to add up to fifty-nine years of life" (p. 79). Although Mrs Boles "doesn't fear [Lynch's] tape recorder ... she remains reluctant to talk about the nature of 'the thing' that has brought her to the hospital", yet cancer struck her just as it struck everyone else despite her active denial, as Lynch writes:

Her doctor, Joe Feller, tells us that a tumour the size of a melon was removed from Mrs Bole's stomach five months ago, but it is growing again. I can see the round lump, the new growth makes beneath her bedclothes. Mrs Boles watches Dr Feller as he bends over her and places his hands on her arm, then on her belly. Her eyes are wide with awe, and for the first time since I've met her, she is speechless (p. 80).

⁴¹ Couser, *Recovering Bodies*, p.59.

Although Mrs Boles is “speechless” about her own illness and suffering, it is Lynch who witnesses the former’s cancer experience and how it is told through her wound:

I am staring at Mrs. Boles. Industrial-size staples close the ten-inch incision in her belly and tubes hang from her nose and her arm. But there she is, in Recovery the day after surgery, talking excitedly, even smiling. I smile back. I am coming to like her, though to be honest, when we first met, she seemed so thoughtlessly alive. All those soap operas and leaving everything to her doctors, dodging and fending off the truths of her cancer. I hadn’t realised how essentially alone she was with her illness (pp. 89-90).

There are no injured, gory, or absent body parts in Lynch’s description of Mrs Boles’ wounds. What is missing is Mrs Boles’ own voice – silence in the form of vehement denial and muted suffering during treatment. It is through this act of witnessing that Lynch is able to find her voice amid her own mutedness and re-tell the stories *through* others’ experiences. In contrast to Stacey’s brief encounter with the stranger in Crete, Lynch is able to re-contextualise her own painful memories in two ways. First, by using the site of another’s wound (also caused by cancer in a body that has just undergone an operation) and second, by documenting another patient’s experience. Thus, seeing Mrs Boles’ wound (without having to exchange information) makes Lynch’s experience more than just a confrontation with a mirrored reality of an Other with the same illness. As the moment moves and shifts, comprehension of both Mrs Boles and Lynch’s wounds can fall simultaneously on multiple simultaneities and in multiple spaces (e.g., the space of the book, the space of the hospital, and the space of the reader reading the book). Mrs Boles’ story, once represented by a timearc, merges with Lynch’s own as she witnesses. Connected, these timearcs then slide down the same spiral and suffering becomes bearable because the *not-there* is made present when the narrator also serves as a witness to create a shared experience that is visually communicable.

Another patient documented in *Exploding* offers a particularly powerful example of cancer as an absent and unseen ‘ghostly’ image. Mrs Powers suffers from a breast cancer that has spread to her brain, causing her to lose her eyesight. Yet that does not stop her from “sensing” that something is wrong with Mary Storelli, her roommate and a fellow cancer patient:

I was going to make some coffee to celebrate the blue sky, but as I went by the curtain of Mary’s bed I sensed that something was wrong. I went to get the doctors, and they said she had been in great pain and was gone. There was nothing to say, so I went back to the room and sent a little prayer out the window to that beautiful sky. If you take a picture, please include that bed as a sign of respect for her being gone (p. 94).

On the opposing page, we see a close-up of Mrs Powers sitting on her bed, taken from her chest up. She is not looking directly at the camera, but rather up and to her left, possibly out the window at the blue sky, but the focus of the photo is the empty bed behind her, where Mary used to be. The deceased’s absence does not cause the viewer to “shudder”, but it is precisely this absence in the room that makes the picture on the next page even more “difficult” to look at. On the next page is a full-spread close-up of Mrs Powers’ head on a pillow (see Figure 2).



(Figure 2)⁴²

⁴² Lynch, pp. 96-7.

A hand is holding one of hers while another cradles her head with its thinning, white hair. Perhaps it is her closed eyes, but her head appears small and fragile against the hand. What really draws our attention and subsequently compels us to let our gaze linger, is the dark, cross-shaped radiation mark on her temple, which appears to stare, intimidatingly. We turn the page, hoping to find a reprieve, but the narrative gives us nothing more than Mrs Powers' testimony about her courses of cancer treatment at the hospital: "After the mastectomy I had radiation four times a week for five weeks and was scared to death each time ..."; "You know it's not so different from when we were kids. In Hanson, Massachusetts, there was a TB hospital. Tuberculosis was a bad disease ..."; or "My eyes? I woke up one morning and I couldn't see anything. It was the Fourth of July, and I was just back from being in the hospital with pneumonia ..." (pp. 98-9). What we see in these two photographs of Mrs Powers and their accompanying narrative is not about the suffering generated by an illness. Our curiosity about the reason for the mark and its meaning is never satisfied, at least not by the images or the textual narratives. There is no scarred or deteriorating body with its wounds staring at us, yet we are aware that cancer has maliciously marked the head of Mrs Powers' – reminding us that it has visited its ravages on her body and her life story. Perez argued that photography, like narrative, begs for continuation.⁴³ As such, the narrative sequence of these two consecutive images implies that the cancer ghost – the unseen presence in the empty bed – has reconstituted itself in the form of a glaring, black mark on her neighbour's temple.

It is also the negative presence that touches us, evoking an affective response. In her study on "enactive witnessing", Patricia Ticineto Clough notes that there are cases in which the subject cannot speak about the traumatic experience, such that the body sometimes serves as a substitute for speech. She argued that rather than using

⁴³ Perez, *The Material Ghost*, p. 52.

language to speak, it can be used to “touch” within an “affective relationship of enactive witnessing”.⁴⁴ Similarly, by turning to the page in *Exploding* and looking at Mrs Powers’ mark, we witness her suffering over and over, not through language, but through what has not been said about her cancer. Not only are we touched by Mary’s absence in the empty bed. We see the pictures and our eyes linger – wanting to make sense of other people’s suffering. Seeing requires that we lean closer to examine more of both what is there and what is implied by a negative presence, until we are finally touched by what we see. Seeing implicates the comprehension of these portrayals of suffering borne by the body. It does not make us turn away – not from Mrs Powers’ fragile body, her resting eyes, or her cancer that is now leaving its signature in a black cross that speaks of individual pain and suffering rendered in a sign of resignation. In other words, we do not wish to, nor can we, turn away from her dying. In contrast, it makes us want to know more.

The End

It is the ending of *Exploding* that makes everything *else* ghostly. As we follow Lynch’s written narrative, we read about her remission (with “four separate scares” (p. 137) of recurrence) and her subsequent recurrence (“I sit here crying and crying, unable to pull myself together ... The second shoe has finally dropped”) (p. 145). We also learn about her decision to try naturopathic/macrobiotic therapy and every detail of her radiation, steroid treatment, and how the drugs used in chemotherapy make her skin, tongue, mouth, brain, and dreams feel after each anti-cancer treatment. Finally, as the reader notices that the right side of the book is beginning to feel much lighter than the left side, we come to understand (no matter how unwillingly) that there is no way she is going to get any better with these

⁴⁴ Patricia Tincineto Clough, “Reflections on Sessions Early in an Analysis: Trauma, Affect and ‘Enactive Witnessing,’” *Women & Performance: A Journal of Feminist Theory* (Vol. 19, No. 2, 2009), p. 150.

treatments, nor is there new hope to be discovered in the remaining pages. Lynch is also aware of this, because she is the one who gets to choose and control how to end her narrative, but when she describes feeling that her handwriting is not her own and notes that “Methotrexate, one of the three chemotherapy drugs to be used, can damage the brain” (pp. 154-5), it is also justifiable to wonder if it is ultimately her cancer that gets to plot the end(ing), as evidenced by the shift in subject pronoun from “I” to “you”:

Hospital. Six o'clock in the morning. What you miss most is the fresh air. This is a tomb. We are sealed in, with all of us clamouring to get out, to breathe, to get better, or to get a stronger sleeping pill. What wakes you again and again are the voices, the footsteps, the heavy roll of the portable scale” (p. 161).

Inevitably, as if wrenching her voice back from the unknown speaker, Lynch asserts her existence by writing the following (last) paragraph:

I think of the young daughter in Satyajit Ray's Pather Panchali, spinning, whirling in the rain, her hair flying out like a flag the night she died. I think of Sally Powers, who had just turned seventy. No one is special, are they, when all is said and done? And, of course, each of us is very special, very singular, carrying weight. I matter. Sally mattered. I would like to open the window tonight and yell that outside. I matter. Or go down and lie next to the plants and whisper it (p. 161, underline original).

This ending would have left the reader with a false sense of self-assurance. It matters, as Lynch repeatedly says, because it is her life and her death, but the weight is getting lighter and lighter as the “I” becomes inevitably insignificant and vulnerable.

Just when we think this is the end of her story, we are presented with two photographs of Lynch. These images are examples of what Radley defined as “difficult” pictures to look at because what we are asked to see is at once too much, and too little.⁴⁵ In the first image, the inarticulacy of the pain is situated at the site of her wounded body in the absence of her breast. Lynch is lying on a table as a doctor

⁴⁵ Radley, *Portrayals of Suffering*, p. 4.

holds up her bandaged arm, such that the sutured wound and the bandaged drainage tube are both open to view. She is looking ahead with her glasses on as if someone were standing at the end of the table talking to her. The room appears dark except for the overhead light above her naked chest. The light draws our attention to her bare remaining breast and the gash where her other breast once was. We are trying to make sense of this image. The sight of the wound (one that we do not normally get to see in orthodox images of breast cancer) is immediate, but the darkened background tells us very little about Lynch's circumstances. We turn the page to seek for more clues and are confronted by the same picture, only this time it is a close-up. The gash looks bigger and the background has diminished to blackness. Cancer and its ghostly presence take centre stage. Indeed, the reader does not get a reprieve from this recurring portrait of suffering until Richards' voice appears on the very last page to inform us of Lynch's death. If that does not count as an ending to her cancer narrative (because we are innately incapable of writing our own death the way we write our own life, e.g., euthanasia), then we must settle for cancer's plot, which makes its presence everlasting (if only for us).

Using Lynch and Richards' *Exploding Into Life* as a key text for analysis in this chapter, I have explained how cancer's negative presence, reconstituted in the form of a ghost, appears in a cancer narrative to haunt us between the lines. I argued that by structuring the cancer experience into timearcs (instead of understanding it according to the timeline), it is possible to free cancer from the conventional diagnosis-treatment-prognosis trajectory and creates a different narrative space. And it is a space that at once contains the past and present; denial and fear, cancer's haunting in the dark and cancer's mark on a fragile body. Together, they allow a possibility for us, as readers, to witness a collective story of cancer.

Chapter Three – “Laughing Matters” in Cancer Films

Cancer has never been considered a suitable subject for conversation at the dinner table. It is a serious matter and can be quite difficult to discuss with one's family members if one is diagnosed with the disease. Cancer is certainly not a laughing matter. Hence, when the story of someone else's cancer is portrayed in a commercial film, there is always the danger of making light of something solemn, particularly with a life-threatening disease such as cancer, which is so closely linked to matters of life and death. This chapter focuses on what these cancer-themed films, specifically comic ones, can tell us about the cancer experience. I argue that as an illness, cancer, when portrayed on-screen, engages the audience's emotions differently than its epidemic counterparts or AIDS. Indeed, the films I have chosen to analyse are categorised as comedies, and by expressing what has been suppressed and silenced by cancer patients themselves, they can paradoxically help shape our popular, lay understanding of the disease.

What makes a film a “cancer film”? When medical historian, Susan Lederer, researched the representation of cancer in popular Hollywood films, she found that even in the canonical *American Film Institute Catalogue*, the list of films that include a depiction of cancer varies according to the search term used, such as “cancer”, “tumour”, or even “incurable disease”.¹ There are as many films in which cancer is only fleetingly mentioned in the dialogue among characters as there are films in which the disease is given centre-stage. If one of the main characters in a film is diagnosed with cancer, does that mean that it is about cancer? What filmic genre is typically associated with films about serious, life-threatening illness? Horror? (Medical) Drama? Romance? What roles can cancer play in visual and filmic narratives? At

¹ Susan E. Lederer, “Dark Victory: Cancer and Popular Hollywood Film,” *Bulletin of the History of Medicine* (Vol. 81, No. 1, 2007) pp. 98-9.

the time of writing this thesis, it is rare to come up with a research paper on cancer films among academics in the field of medical humanities and film studies. Apart from the shortage of clear definitions, perhaps one of the reasons for this lack is that, unlike illness narratives that are authored by the patient, these fictional stories of cancer do not necessarily centre on a patient's illness experience. Hence, they lack authenticity. In addition, cancer films are not concerned with patients' construction of meaning through the retelling of their stories. Instead, most on-screen cancers follow the generic convention of a death narrative with cancer as a plot device that sets the story in motion rather than intervening in an on-going account. Likewise, the film often ends with a cancer-related death (one exception is a 2010 French film that I discuss in greater detail in Chapter Six).

Popular cancer films are a form of cultural commodity, and like all commodities, they are designed and packaged to suit the tastes of the masses. In this chapter, I discuss the history of how films have been used to represent diseases in Western culture. I also show how the cancer film genre has evolved with the audience's attitudes and knowledge about the disease, such that the role that cancer plays in these films has changed accordingly. From educational films, particularly during the early 1900s, to gender-stereotyped and melodramatic (young females exclusively portrayed as morose cancer patients), to funny and light-hearted, I show that the progression of on-screen cancer is all about creating a collective emotional experience for the audience.

I then focus on the Hollywood comedy *The Bucket List* (Dir. Rob Reiner, 2007) to show how cancer can function as an "ellipsis" that signifies an omission that cannot be fully articulated and expresses the mood, tonality, and gestures of a patient's attempts to cope with a disease that can only be immediately replaced and displaced

by a series of unrelated thoughts/actions. This not only leaves room for the narrative to be cushioned with humour (due to the gap created by the ellipses between each action/thought), but also fills the gap with meanings that encourage both the protagonist and the audience to contemplate what it means to be dying of cancer.

I also analyse the Hong Kong film, *2 Become 1* (Dir. Wing-cheong Law, 2006), to further discuss the use of humour in (breast) cancer films. *2 Become 1* is a film about a woman with breast cancer who finds her perfect man, who happens to suffer from erectile dysfunction. In the end, they help each other overcome life's hurdles. Although breast cancer is a particularly sensitive topic because it can reinforce the objectification of women's bodies through biomedical discourse, and while jokes about breasts/cancer are considered disempowering to women, I choose this film precisely because cancer in this case only makes the woman more attractive to her Prince Charming. I juxtapose it with feminist responses to breast cancer humour and argue that the cultural value of mainstream (breast) cancer films lies partly in the way they sugar-coat and normalise the disease. More importantly, these on-screen cancers are both fairy tales and anecdotes that ground the patient (as mother/father/son/daughter/partner/neighbour) in the mundane, everyday life from which they must cope with matters of life and death, which relegates the illness experience to just one part of the life cycle. The best part is that they will ultimately live "happily ever after".

The Early Use of Filmic Representations of Disease

Images of catastrophe increasingly assault us through the media, such that the world is reeling from the (visual) effects of war, natural disasters, famine, and terrorist acts. Even congenital diseases and other degenerative/chronic illnesses are being broadcasted by various philanthropic advertising campaigns and charity groups such

as the Children's Cancer Foundation, the American Cancer Society, Orbis, and Oxfam. We have grown accustomed to seeing visual representations of other people's suffering and pain. For the lay audience, the mass media (such as magazines, movies, and TV – particularly documentaries and featured stories) serves as the common source of both medical knowledge about illness and health, and entertainment. Scientific, jargon-free narratives with mass-appeal and colourful images that cater specially to lay people's tastes are presented on TV programmes broadcast by the Discovery Channel, SBS, or other prime-time television networks and are easily taken as verified scientific truth. The fact that most of these programmes usually invite medical professionals to consult and offer advice reveals an attempt to make the program realistic enough that the featured disease becomes a common medical issue that could happen to anyone. More important to the audience is the opportunity to see how others live with their physical illnesses on-screen without the discomfort of real-life interaction. Interestingly, common illnesses such as flu or heart disease are rarely featured. What we do see are diseases that are rare or sensational and they are chosen because they are considered "interesting" to the audience from the producer's perspective. Seeing someone's illness portrayed graphically on-screen fulfils our curiosity about what disease does to the human body without having to experience it first-hand. To a certain extent, it is instant gratification without having to empathise.

The visual representation of disease in motion pictures has come a long way since the Lumière brothers' invention of the Cinématographe, an instrument for recording and projecting living motion.² Ever since, the technology of visualisation

² August Lumière's obituary, printed in the biographical files of the New York Academy of Medicine, extolled his lifelong commitment to medical biology, pharmacology, and experimental physiology. The invention of the Cinématographe by the Lumière brothers, which has helped the design and production of specialised cameras and film stock for the laboratories of scientists and physicians, is considered to have indirectly affected the advancement of French public health and the prolongation of the average lifespan (see Lisa Cartwright, *Screening the Body*, (Minneapolis: University of Minnesota Press, 1996) 1-2.).

has offered new ways of understanding and internalising health and illness. Take epidemics such as SARS (Severe Acute Respiratory Syndrome) or the Swine Flu (the H1N1 virus strain) for example. Projecting on-screen what is not visible to the naked eyes characterises the virus as a villain that attacks and invades the body of the innocent “victim”. Such visual depictions of health affect our understanding and imagination of the “global”. Seeing how an epidemic has impacted not just the health of the individual, but that of the world as a whole – socially, politically, and economically – affects the national policies and securities of global health.³ Another example is the visualisation of the hazards of tobacco smoke. Such visual representations reveal how the toxic substance in tobacco affects different parts of the body, such that even second-hand smoke can now be imagined as “travelling” and “spreading” across invisible barriers in our public spaces to “enter” and “invade” the innocent, clean spaces occupied by non-smokers.⁴ These images shift our focus from “disease” to “health risks” with the emphasis on (self) surveillance commonly advocated as a result.

Cancer films serve a different purpose than their epidemic predecessors.

Given the success that crusaders against tuberculosis and venereal diseases have had using motion pictures for public education, cancer also made its debut appearance on-screen in 1921 in a U.S. public health movie. The film, entitled *Reward of Courage*, is essentially a love story about a woman’s cancer diagnosis.⁵ It was not a cinematic

³ In the case of the 2009 swine flu outbreak, the import of pork and live pigs was banned for health and safety reasons, which sparked fear that such protectionism that would jeopardise the global economy.

⁴ Roddy Reid, “Unsafe at Any Distance: Todd Haynes’ Visual Culture of Health and Risk,” *Film Quarterly* (Vol. 51, No. 3, Spring 1998), p. 33.

⁵ *Reward of Courage* features a female cancer patient who wants to break off her engagement to her fiancé based on a fear that cancer is hereditary and that she might pass it on if she were to have children. The patient’s mother, who has mistaken the interest in her daughter exhibited by her future son-in-law (who is also a doctor specialising in cancer) as merely mercenary, is about to opt for a “quack” treatment. Thankfully, the patient’s father and the young doctor arrive in time to arrest the quack practitioner just as the mother is about to hand over her money. In the end, the patient’s cancer is cured by the young doctor and they marry and have a healthy baby together. The movie closes on a happy family scene (see David Cantor, “Uncertain enthusiasm,” pp. 43–4).

success, nor was it intended as such, in part because the nature of the disease does not lend itself to delivering a sense of awe to the audience. According to medical historian, David Cantor, early cancer movies were only used for institutional propaganda to educate the public and establish that cancer is neither contagious, nor hereditary. Most importantly, this early form of public health education aimed at teaching individuals to identify the early signs of cancer while encouraging them to go for regular check-ups and seek medical treatment if a tumour was suspected.⁶ Despite this educational mission, there has always been a major concern that revealing too much “truth” about cancer on-screen might drive patients away by implying the need for radical treatment. It is also troubling that the patient could lose confidence in her physician if she realises that nothing is certain until further medical research reveals more because, to date, there is no 100% successful cure for cancer. Cantor also noted that in the beginning, institutions such as the American Society for the Control of Cancer (ACSS, now known as the American Cancer Society) were concerned about the fear that images of cancer’s radical treatments incited in the public; specifically, that such images might ultimately prompt patients to avoid going in for check-ups. As Frank J. Osborne, the then Executive Secretary of the ASCC explained about the elimination of all operative techniques and hospital scenes in *Reward of Courage*:

I believe the public will respond much more readily to the suggestion of immediate attention to anything suggesting cancer, if the arrangements for radical treatment are kept in the background and left to the physician after the patient has applied for advice.⁷

Although visual imaging in cinema has been an effective way for governments and health institutions to popularise the ideals of local and global health, the cancer

⁶ David Cantor, “Uncertain Enthusiasm: The American Cancer Society, Public Education, and the Problems of the Movie, 1921-1960,” *Bulletin of the History of Medicine* (Vol. 81, No. 1, 2007) pp. 40-42.

⁷ Frank J. Osborne to W.S. Richardson, 29 July 1921, Laura Spelman Rockefeller Memorial Archives, series III, box 5, folder “American Society for the Control of cancer, 1921-23,” Rockefeller Archive Center, Sleepy Hollow, N.Y. (Cited from David Cantor, “Uncertain Enthusiasm,” p. 44).

film genre limits the ways in which the cancer story can be told. At the time, a public health education film's primary concern was to make health threats conveniently visible to and easily identifiable by the general public. In epidemic cinema, it is the visibility of a virus and its means of spreading as presented on-screen that marked the boundary between "self" and "other". For Hollywood films such as *Outbreak* (Dir. Wolfgang Petersen, 1997), *12 Monkeys* (Dir. Terry Gilliam, 1995), and *28 Days Later* (Dir. Danny Boyle, 2002)⁸ to be entertaining and successful, the filmmakers incorporated elements of horror that put the audience at ease by confirming that they were merely works of fiction (or re-makes of something that had already happened before).⁹ Epidemic cinema presents stories in such a way that the audience, while not likely to feel paranoid about an imminent disaster, experience a genuine sense of fear about a terrifying but remote event, as explained by Pappas and colleagues:

Of all medical specialties, infectious disease seems to be the only specialty that can offer cinema the required suspense. Memories of great epidemics and continuously available information on new epidemics and dangerous viruses have embedded in the public a sense of awe about infection, a prerequisite for cinematic success [...] One should never forget that some of these trends have subsequently been adopted by the public as facts, and, therefore, they act as determinants of public reactions to possible future infectious outbreaks and, perhaps, government policies.¹⁰

However, the images in cancer films lack the "required suspense" to distance the audience from the narrative and reality. In fact, cancer films often initiate a convergence of the narrative and reality that tells the audience: *this is real and it could happen to you*. For cancer films to be popular, the images of dying cancer patients must be perpetuated in a way that ensures that the human suffering appears non-violent, but still credible and voyeuristic. In addition, on-screen cancer suffering also

⁸ These are examples of Hollywood blockbusters about global epidemic outbreaks that result in the creation of new worlds and orders.

⁹ *Plague Fighters* (Dir. Ric Bienstock, 1996) and *Influenza 1918* (PBS, 1998) are two examples of documentary drama that are produced to document and frame the "facts" about a specific disease, specifically Ebola Haemorrhage Fever and the 1918 Influenza pandemic, respectively.

¹⁰ Georgios Pappas et al., "Infectious Diseases in Cinema: Virus Hunters and Killer Microbes," *Clinical Infectious Diseases* (Vol. 37, 2003) 939.

typically includes a remission period that is used for the protagonist's self-reinvention and serves as a potential emotional ingredient in the dramatic effect that appeals to mass audiences. In addition, without any "monstrous Other" represented on-screen, cancer films cannot rely on visibility and signs to typecast the disease and must instead "internalise" the patient's body as the "Other", which paves the way for the addition of unhealthy lifestyles, the polluted environment, the poor quality of human relationships, and even work-related stress to the current stock of significations – each of which can be translated into a different story about cancer on-screen.

The Cancer Film Genre

The choice of genre decides what kind of experience can be told about a particular disease. This is also a reflection of the cultural values that shape the popular discourse of each illness. In her exploration of the role early 1930s-70s Hollywood films played in the cultural production of cancer, Lederer identified the historical development of cinematic cancer as part of the "epidemic entertainments" that portray diseases as cultural commodities. She argued that these portrayals, when viewed today, perform the function of informing today's audiences of the past (American) audiences' attitudes about cancer and the role of medical research in overcoming the dread disease.¹¹ Furthermore, the verisimilitudes of cancer are typically not taken seriously and filmmakers, driven by the need to draw the interests of audiences from all walks of life, usually gloss over the disease, which results in the characters only becoming physically weak and eventually dying without undergoing any gross transformations. These are what Sperling later called the "basic cancer movie plots",¹² the most typical of which range from having the dying patient finally

¹¹ Lederer, "Dark Victory," pp. 94-115.

¹² Gary Sperling, a journalist/writer for the online magazine, *Slate*, proposed the "All-Cancer Film Festival" in 2002 when he, too, was undergoing chemotherapy. It was hoped that such an event would provide an opportunity for cancer patients worldwide to identify and to learn from watching "cancer

shake off the ennui, which is what really rendered him lifeless in the first place, and start doing things that are meaningful to his life (e.g., *Ikiru*, 1958) to showing that the patient must simply shed his anger and embrace the love of his life (e.g., *My Life*, 1993) or having the patient use the rest of her time to rebuild broken relationships (e.g., *Life as a House*, 2001). Towards the late 2000s, most cancer-themed films and even TV dramas were not shy about depicting cancer patients more faithfully and realistically (e.g., *My Sister's Keeper*, 2009), perhaps because the suppression of dramatic elements deemed too removed from ordinary, off-screen lives has triggered patient-writers such as Sperling to criticise Hollywood cancer-themed films for being incapable of conveying what it is really like to live with cancer and unwilling to provide a communal cancer experience:

What's stranger is that cancer movies have failed to absorb the ubiquitous self-help literature that comes along with the disease. (Search "cancer" on Amazon.com, and get ready to wade through over 8,000 listings, many of which boil down to "Take control of your illness" and "Ask questions.") This is understandable in the early films, made when a doctor's authority was sacrosanct, but it's odd in an era of patient activism.¹³

Although the abovementioned plots have been subject to unanimous criticism for offering insufficient representations of the disease in popular films, they nonetheless demonstrate that they have evolved together with audiences' attitudes about cancer.

Indeed, the generic evolution of cancer films actually shares a lot of similarities with the trajectory of AIDS films – from medical TV dramas to mainstream popular (Hollywood) films – and offers insight into why cancer films are the way they are in Hollywood. This is not to say that cancer and AIDS have the same cultural meanings, but Paula Treichler brings our attention to the relation

movies". He claimed that the basic cancer movie plot includes a valuable lesson that can be learned by witnessing the suffering of a loved one's cancer experience (Source: <http://www.slate.com/id/2065895>, accessed on 19 Feb, 2010).

¹³ Source: <http://www.slate.com/id/2065895/> (accessed 1 Feb 2010).

between Hollywood and AIDS when she explained why AIDS narratives have never achieved the cinematic success of other epidemic films:

Hollywood's addiction to the bottom line and therefore to upbeat endings; presumed audience intolerance for anything about AIDS; the physical unattractiveness of AIDS as a disease; and the entrenched nature of gay caricatures in Hollywood. That Randy Shilt's bestseller *And the Band Played On* so clearly displayed these ingredients perhaps explains its problematic and ultimately failed transition to theatrical film.¹⁴

When we look at on-screen cancer and wonder why "cancer films" are not considered a filmic genre, it is precisely what the disease *does not* stand for that becomes problematic in such a transition. Most cancer themes are devoid of the controversial issues that allow films or even TV to claim that their production values have a serious social edge (breast cancer, as subsequently discussed, is the only exception). Worse still, unlike AIDS and homosexuality, which can be domesticated, cancer is not a disease that can engage the audience imaginatively. For example, how can we talk about bowel cancer? What social or ethical issues are involved about this disease that can enable us to change the way we understand the disease? Hence, in the case of on-screen cancer, the problem is not necessarily the need to meet Hollywood's "bottom line". It does, however, reflect the impossibility of attempting to portray cancer experiences within a conventional narrative structure through visual representation alone. There is no universally recognisable image of a cancer patient, just as there are no definitive images of people with HIV.

Despite their limitations and shortcomings, Lederer argued that films like *Dark Victory*, a Hollywood melodrama about a woman with a brain tumour that has doomed her to an early death, have nonetheless contributed to enhancing the cultural literacy of cancer, which reflected how the disease was perceived at the time. Even if the film veiled cancer's physical realities by reassuringly downplaying its effect, such

¹⁴ Paula Treichler, *How to Have Theory in an Epidemic*. (Durham and London: Duke University Press, 1999) 182.

that “its contours could be traced in the dark”,¹⁵ as Lederer notes, the advertising for the film at the time of its release did not mention the brain tumour that the main character, Judith Traherne (played by Bette Davis), suffers from. Instead, the entire film was framed as “the love story no woman will ever forget”.¹⁶ *Dark Victory* proved both a popular and critical success, particularly among female audiences.¹⁷ In her attempt to articulate why a film like *Dark Victory* might have such box-office appeal, Lederer turned to the way the director deals with the cancer’s effects. First, as a brain cancer patient, Traherne mostly experiences headaches, at times misjudging distances, and once burning her finger without even realising it. Second, her brain surgery results in little more than her shaved head, which is fashionably concealed with headscarves. The film also makes it obvious that Traherne is the only person who believes that she has been cured while the doctors, her friends, and even the audience know that she is dying. The film fades to an end with Traherne, alone in her bed, losing her eyesight as the cancer recurs. In this representation, cancer is more tragic than scary because the patient dies an innocent, poetic death having conformed to the (female) sick role throughout the film.

Cancer dramas such as *Dark Victory* touch on our existence, but they also reach deeper into our life histories and dark memories to highlight any tragic vulnerability while leaving the physical body more or less intact. Since the release of *Dark Victory* in 1939, the subsequent sixty years have seen a variety of cancer films from Hollywood and cinemas worldwide, including *Tokyo Tower: Mom and Me, and Sometimes Dad* (Dir. Joji Matsuoka, 2007); *Marvin’s Room* (Dir. Jerry Zaks, 1996); *My Sister’s Keeper* (Dir. Nick Cassavetes, 2009); *Sweet November* (Dir. Pat

¹⁵ Lederer, “Dark Victory,” p. 97.

¹⁶ Matthew Kennedy, *Edmund Goulding’s Dark Victory: Hollywood’s Genius Bad Boy* (Madison: University of Wisconsin Press, 2004) 184. (Cited in Lederer, p. 105).

¹⁷ Lederer, “Dark Victory,” p. 105.

O'Connor, 2001); *Love and Other Drugs* (Dir. Edward Zwick, 2010); *Stepmom* (Dir. Chris Columbus, 1998); *Christmas in August* (Dir. Jin-ho Hur, 1998); *Flower Island* (Dir. Il-Gon Song, 2001); *Funeral March* (Dir. Joe Ma, 2001); and many more.

While some of these films have been more commercially successful than others, each uses very different aspects of cancer to tell their stories. For example, *My Sister's Keeper* is concerned with the ethical issues generated when one child is conceived as an organ donor for a dying sibling, whereas *Sweet November* is a mainstream love story in which the main character falls in love with a dying cancer patient. Granted, the gender convention of female patients and male physicians established in popular medical narratives is still reinforced, but the "gendered understanding of cancer" that characterised 1930-40s cinematic portrayals has slowly faded in subsequent popular cancer discourse.¹⁸

Although cancer is no longer a mysterious disease and celebrities (e.g., Kylie Minogue, Rupert Murdoch, and Melanie Griffith, to name a few) have publicly announced their diagnoses, there remain a very limited number of ways to portray cancer on-screen. Suffering is typically represented by a headscarf or hat that implies baldness resulting from chemotherapy and occasionally it is suggested that the character with cancer is throwing up, bleeding (as in leukaemia), or, in the case of a brain tumour, losing physical coordination. Cancer, as a disease without many physical conditions that can be dramatised on-screen, is not cinematically "exciting", and neither is the fear that it generates the kind that can be used by filmmakers to create an apprehensive mood comparable to those that fuel epidemic cinema, in which

¹⁸ Lederer remarked that organisations such as the ACCS usually targeted women in their propaganda about cancer prevention and treatment. Women (in the US) were recruited to join various women's clubs to "foster the women's Field Army", which was organised to fight cancer with knowledge. This gendered understanding of cancer was so deeply ingrained in the minds of the public that some even believed that cancer was an exclusively female disease. It was this realisation that prompted the ACCS to see it as a problem that required remediation.

dying patients (men, women, and children) are just one element in a long list of gratifying (female) fatalities feeding the audience.

The Role of Cancer in Cancer Films

Use of the word “cancer” has become increasingly common on TV (even in sitcoms) and in the cinema, but not all of these occurrences are related to portraying an illness experience for the audience. The word “cancer” floats around the mass media as if to remind the world of what a common disease it is. In *Signs of Life: Cinema and Medicine*, Brian Glasser even suggests that cancer has become the “cinematic sickness of choice” in both art house and mainstream cinema,¹⁹ implying not only a link to the global rise in cancer cases each year, but also the versatility of the disease because it appears to fit easily within most conventional genres.

Cancer’s cinematic role is similar to that of the ghost in ghost films. Ghost films, which are fictitious films about ghostly spirits, differ from the real-life accounts of individuals who have actually encountered ghosts. The purpose of the former is not to tell truthful stories about what ghosts/spirits look like, but rather to appeal to the audience’s interest through visuals. Such films need not be factually convincing and can belong in a variety of genres including horror, romance, and even comedy. In addition, the “ghosts” in these films can take on myriad forms, from Freddy Krueger (in *Friday the 13th*) or Patrick Swayze (in *Ghost*) to Sadako Yamamura (in *Ringu*) or pure visual effects (e.g., *The Sixth Sense*, *The Mist*, *The Exorcist*). The “ghosts” in the abovementioned films, whether implied or played by an actor, play roles in their respective narratives. Likewise, cancer films can take the form of a love story, a

¹⁹ Brian Glasser, “Magic Bullets, Dark Victories and Cold Comforts: Some Preliminary Observations about Stories of Sickness in Cinema,” *Signs of Life: Cinema and Medicine*, ed. Graeme Harper and Andrew Moor (London and New York: Wallflower Press, 2005) 14.

psycho-thriller, or a melodrama and regardless of how cancer is manifested on-screen, its role, like that of a ghost, is to herald death.

When the main character in a film is a cancer patient, the audience is aware that what they are seeing is not just how a person battles a disease, but how that person, upon knowing that he does not have much longer to live, chooses to live what remains of his life. Thus, cancer in these stories serves as a can-opener that reveals something that has been kept under the lid for a long time. Once uncovered, it is the film's duty to allow the audience to identify with the protagonist as he beats the odds and lives. Inevitably, these films feature cancer as the impetus for a character's conversion from one attitude and set of beliefs to another – a transition that often has a profound effect on the lives of those the patient leaves behind. In this way, cancer, when plotted in these fictional cinematic narratives, becomes a sign such as those identified in Roland Barthes' semiotics, because it is attached to a signification that is as unstable and inherently arbitrary as when a rose is used to signify human romantic passion.²⁰ Thus, rather than serving as a performative act of healing, on-screen cancer is typically used to signify a love that is realised too late with the message that we must look death in the eye to gain the courage to change our doom – if we are lucky enough. This perhaps explains the versatility of on-screen cancer representations. Their unstable signifiers fit into stories about how to come to terms with oneself and one's loved ones, how to deal with fear (both one's own and that of others), and how to let go of an unforgiving past and embrace what remains of the future with dignity. Because the course of the illness and the physical suffering caused by cancer and its treatment are rarely part of the on-screen story, we do not see that which is omnipresent in literary illness narratives; specifically, how a cancer patient negotiates the physical conditions of everyday life. Cancer films are not always about heroism

²⁰ Roland Barthes, *Mythologies*. Trans. Andrew Lavers (London: Cape, 1972), p. 164.

or how an individual can change the world through singular effort. In fact, cancer films stand out from the rest of illness cinema precisely because it does not take the battle against the "sick role" too seriously.

Despite being honest about bringing repressed feelings to the fore in ways that raise awareness of the emotional experiences of cancer patients, one thing missing from these mainstream cancer films is probably its authenticity. As a matter of fact, when a character is facing his mortality, such films inevitably compromise the medical facts of the disease. Scenes are certainly easier to witness when it is clear that they belong to a work of fiction being played out by unrelated actors. However, when all of the focus is on the dramatic emotional element, cancer films must often compromise some of the scientific facts about the disease. For example, even though the five-year survival rate varies from cancer to cancer,²¹ the cancer survival rate has generally increased due to improvements in treatments and a greater awareness of the disease among the public. This has resulted in a more favourable outlook for diagnosed patients in recent years. However, cinematic cancer has never enjoyed this latest victory. In fact, in most films that feature cancer, the type of cancer is not even named and there has been a significant lack of open discussion between oncologists and patients about diagnoses, treatments and prognoses. This is not exclusive to cancer films, as Lisa Cartwright explains in *Screening the Body*:

The film motion study is primarily neither its contribution to a singular dominant industry or optical paradigm nor its contribution to medical knowledge. Its greatest importance is its function as an intertext between popular and professional representations of the body as a site of human life and subjectivity.²²

²¹ According to the American Cancer Society, the five-year survival rate refers to the percentage of patients who live at least five years after their cancer is diagnosed. Five-year rates are used to produce a standard way of discussing prognoses. For example, the five-year survival rate for cervical cancer is 72%, whereas those for colon cancer are 93% and 8% at Stages I and IV, respectively (Source: American Cancer Society www.cancer.org).

²² Lisa Cartwright, "Science and the Cinema," *The Visual Culture Reader*, ed. Nicholas Mirzoeff (London and New York: Routledge, 1998) 201-2.

Referring to cinematic illness narratives in general, Cartwright means that the filmic representations of the body (which can also be related to all other health and illness matters) are not primarily about being factually or scientifically realistic. It is not necessary for professional and popular representation to coincide or achieve a definitively truthful reflection. In fact, the technique of mixing melodrama with propaganda and control messages in a cinematic narrative of illness offers the opportunity for a more flexible representation of illness and storytelling that extends beyond the limits of a biomedical framework or personal accounts. This mixed use of both fiction and documentary is especially common in epidemic cinema such as *The Hot Zone* and *Outbreak*,²³ as Semmler remarks that “these techniques are ploys to activate our innate expectations of the documentary genre and to lull us into a willing suspension of disbelief, thus inducing our acceptance of the incredible events that are to follow.”²⁴ Semmler’s argument is also useful in understanding cinematic narratives about cancer. As the criteria in those early ASCC movies reveal, melodrama is often used to deliver the public health message to mass audiences, whereas purely scientific endeavours such as the 1928 British film, *The Cultivation of Living Tissue*, were deemed too technical to generate public interest at the time.

Therefore, cancer’s on-screen role serves one main purpose: to enable the unique, collective emotive effect that Smith referred to as the audience’s “emotion cues” to engage in an appropriate mood or elicit an emotional response.²⁵ Smith argued that emotion cues can include facial expressions, dialogue, sound, and lighting, but in the case of cancer films, the mention of cancer becomes one of the cues.

²³ *The Hot Zone* is a filmic adaptation of the 1994 best-selling, non-fiction, bio-thriller of the same name by Richard Preston about the origins of the Ebola and Marburg viruses. *Outbreak* is a fictional bio-thriller directed by Wolfgang Petersen in 1995 about a fictional Ebola-like virus known as the Motaba.

²⁴ Iliana Alexandra Semmler, “Ebola Goes Pop: The Filovirus from Literature into Film,” *Literature and Medicine* (Vol. 17, No. 1, 1998) 154.

²⁵ Greg M. Smith, *Film Structure and the Emotion System* (Cambridge: Cambridge University Press, 2003) pp. 7-9.

Cancer as a theme and its connection to doom suggest a protracted death scene that begins in the very first sequence. Once cued, the audience can share a collective emotional experience of the illness together with the characters, particularly when someone is facing the possibility of dying. This is another way of explaining why cancer remains a “cinematic sickness of choice” despite its lack of thematic variation and adhesion to medical reality.

Ellipses as Emotional Cues

Even with the implacable images that continue to dictate the on-screen portrayal of cancer, the Hollywood film *The Bucket List* exemplifies the changed tone and mood of recent cancer-themed films when dealing with life and death. The film features two sexagenarians, each of whom is facing his own terminal cancer. The story begins with Carter (a mechanic played by Morgan Freeman) being told over the telephone that he has cancer. The background of this scene tells us that he is at work in a garage. The cigarette dangling from between his fingers drops when he hears the news. The next scene introduces Edward (a billionaire played by Jack Nicholson), who is diagnosed with an un-named cancer. He also happens to own the hospital to which Carter is later admitted and due to his own money-saving regulation, which states that two people must share a room under any circumstance, the two are made to share a hospital room. A friendship subsequently forms between them and knowing that they do not have much time left (perhaps due to the nature of their respective cancers or their age), during one of their conversations a “bucket list” – a list of things that the two men would like to do before they “kick the bucket” – is created in response to a casual suggestion made by Carter. The list includes kissing the most beautiful girl in the world, helping a stranger for the good of it, seeing something truly majestic, and travelling to different parts of the world. Backed by Edward’s fortune,

the two of them set off from the hospital to make their last wishes come true despite the objection of Carter's wife. Their adventures comprise the rest of the movie.

Throughout this particular film, there is only one scene that shows the two protagonists taking turns shivering in their hospital beds; an implication of the high fever and cold sweats that accompany cancer treatment. Each has his back facing the other while the other helplessly looks on. They each witness the other's suffering when their own side effects have subdued, and because their backs are turned to the camera as well, the audience is left to imagine their experience. Moreover, we are not shown how Carter and Edward feel after they hear their diagnoses. Thus, in *The Bucket List*, cancer functions as an ellipsis. An ellipsis represents neither a finished statement, nor a question; it stands for an incomplete thought and signifies an omission that cannot be articulated. For instance, when a phone call from a faceless, unknown person informs Carter that he is ill during the first scene, Carter can only respond by muttering to himself: "I have cancer ...". The omission does not change or disrupt the meaning of what the scene has established, it simply represents thoughts that cannot be expressed and urges the audience to settle into a particular mood. The ellipsis sets the mood, tonality, and gesture of the event. Another example would be the silent scene during which they witness each other's suffering from their respective cancer treatments. This scene shifts smoothly into the next scene, in which they feel better and are ready to pursue the wildest, most rebellious things against sound advice. Here, the ellipsis (the unspoken) is there expressly to be replaced by a series of unrelated actions filled with new meaning that divert the fear of the unspeakable (death and suffering), which has no role or dialogue in the film.

I argue that it is precisely what is not explicitly shown on-screen that plays a more important part in the emotional build-up for this cinematic form of cancer

narrative. In their analysis of how narrative organises a field of signification to structure a story, Cohan and Shires argued that there is a basic linear organisation of events that constitutes narrative movement syntagmatically and paradigmatically. In most narratives within a given story structure, a sequence of events is arranged to lend the structure logic and order. Cohan and Shires called this a syntagmatic structure. A paradigmatic story structure stresses “the importance of closure as a means of containing the movement of narrativity which the syntagmatic structure produces”. Thus, a paradigmatic structure frames the narrative and requires the “*displacement* of both the initial and the closing events”.²⁶ In the example of *The Bucket List*, the film opens with Carter’s voice-over, saying: “Edward Cole died in May ... He was eighty-one years old. ... I know that when he died, his eyes were closed, but his heart was open.” The film ends with another monologue delivered by Carter via voice-over as the audience looks at the mountain where Edward is buried. If the news of Carter’s diagnosis is the placement of the initial event that sets *The Bucket List* in motion, the ending is metaphorically *replaced* by the good memories of the meaningful life that he and Edward have left behind. Despite the fact that Carter dies before Edward in the film, Carter’s closing monologue implies that life continues in another space and time. In a letter to Edward, Carter writes: “[my wife] Virginia said that I left a stranger and came back a husband; I owe that to you.” At Carter’s funeral, Edward makes a speech:

Carter and I saw the world together, which is amazing when you think that only three months ago we were complete strangers. I hope that it doesn't sound selfish of me, but the last months of his life were the best months of mine. He saved my life, and he knew it before I did. I'm deeply proud that this man found it worth his while to know me. In the end, I think it's safe to say that we brought some joy to one another's lives, so one day, when I go to some final resting place, if I happen to wake up next to a certain wall with a gate, I hope that Carter's there to vouch for me and show me the ropes on the other side.

²⁶ Steven Cohan and Linda M. Shires, *Telling Stories: A Theoretical analysis of narrative fiction* (New York and London: Routledge, 1988) pp. 64-66 (emphasis original).

Although painful reminders of death still exist and prevail throughout the film, they never signal finality until the film ends, at which point they echo Carter's opening monologue. Death (from cancer) hangs in a blurred background that is suggestive of the snapshots taken of places Carter and Edward have been and the things they did together. In these photos, only the facial expressions of the two men are highlighted. While the audience knows that they are posing only to show that they are alive and well, the backgrounds (of the places they have been) serve as a constant reminder not just of that one specific moment in life they shared, but also of their deaths – which is not for the audience to see.

The Bucket List is a melodrama with a unique emotional blend of laughter and tears. Assuming that no one finds the word "cancer" uplifting or exciting, it first sets up a poignant mood through various significations to create a personal connection with the audience that reflects the general public's horror and anxiety. This is then sustained or altered according to other emotional moments throughout the movie. Smith explains this mechanism in the following way:

Film structures seek to increase the film's chances of evoking emotion by first creating a predisposition toward experiencing emotion: a mood. Films rely on being able to elicit a lower-level emotional state, which can be established with less concentrated cuing than would be required for emotion. The first task for a film is to create such an emotional orientation towards the film.²⁷

In short, by introducing itself as a sad story about two men dying of a terminal disease, the film can then break free from this prescribed mood and evoke other emotions by using different visual and emotion cues. These cues are crucial elements in constructing the main narrative, which incorporates both what is spoken, and what cannot be said about cancer.

²⁷ Smith, *Film Structure and the Emotion System* p. 42.

As to what extent these constructed emotions are conducive to a collective emotional experience, the word “comedy” plays an important role here. Films such as *The Bucket List* must inject a variety of redundant “emotive cues” to ensure that audience members with different individual emotive systems are nudged towards an appropriate emotional orientation, such that the audience laughs despite the predispository mood. One of the criteria that makes humour possible in *The Bucket List* stems from Edward’s mysterious fortune because the pairing of these two men as mismatched buddies who both only have a limited time to live can only be explained as a coincidence that results in a comedy. It seems to be telling us that in the moments when life seems most hopeless, there are still many possibilities that money and the most unlikely kinds of coincidences can offer. This fairytale comedy manages to transport the audience away from mundane concerns such as financial constraints, familial responsibilities, and physical limitations into a crazy but insightful adventure with the two protagonists. We are willing to go with them because we know they will die in the end (as we all will one day), and we forgive them for their selfish recklessness. Rather than presenting the illness experiences of cancer, turning them into speechless ellipses leaves room for humour to create distance between the narrative and reality. Hence, cancer gives meaning to this adventure and we do not laugh at Carter or Edward because we see that they have cancer, but rather because of what they do despite having cancer.

Contemporary cancer films are free from the responsibility of educating the public about the disease. Because cancer is now common (and commonly discussed), such that most people now know someone who has or had cancer, the cancer film genre has also evolved into a less morbid and dramatic collection than the one that produced *Dark Victory*. Humour is the chief emotional ingredient in recent cancer films, which begin by setting up a dispository mood among the audience as they

realise that the protagonist is dying of a terminal illness. The film is then sprinkled with jokes and humour, such that the general mood is altered and the audience is no longer focused on the fact that the protagonist is dying, but shifts instead to what happens to the protagonist despite that fact. Notably, the patients in today's cancer films are characterised as fighters who, instead of being "wise" (detecting warning signs and seeking treatment in time) or "foolish" (ignoring the danger and dying from cancer), are most often depicted as striving to live after getting over the initial shock and despair of their diagnoses. Such characterisation intensifies the emotive effect, particularly because the audience still expects the protagonist to die from the disease. This expectation establishes a predispository mood in these films, and the peppering of the narrative with humour ensures that the ending is heartening rather than heart breaking. In his study of illness and life, Couser notes that some personal cancer narratives opt for a comic, uplifting, open ending as a form of self-healing, and that cancer films clearly share these same characteristics.²⁸

Do (humorous) cancer films have therapeutic value? The medical effect of using laughter as an intervention is still under scientific debate. However some research has provided evidence that humour and laughter might prevent coronary heart disease and enhance natural "killer cell" activity, which is responsible for our body's immune surveillance. Some scientists believe that humour can indirectly help elevate immunoglobulin levels which, in turn, help clear toxins and bacteria from our blood serum and bodily fluids. According to one report published in *Cancer Investigation*, although there has not been a randomised controlled clinical trial, the "benefits [of laughter] have been reported in geriatrics, oncology, critical care, psychiatry, rehabilitation, rheumatology, home care, palliative care, hospice care,

²⁸ G. Thomas Couser, *Recovering Bodies: Illness, Disability and Life Writing* (Madison: University of Wisconsin Press, 1997) p. 39.

terminal care, and general patient care”.²⁹ Most would agree that there are no ill side effects to doses of laughter and humour in everyday life, and while it is far from being a cure for any disease, it is a proven “coping mechanism” for people under stress. There are on-going collaborations between researchers and hospitals to further investigate the therapeutic value of humour through projects such as the Clown Care Unit, and Laughter Clubs are being organised among patients to reduce stress and pain and improve healing because “studies have shown that 50% of cancer patients used humour and 21% of a group of breast cancer patients used humour or laughter therapy.”³⁰ It has also been suggested that humour be used during the physician/patient interactions in clinical settings – a practice that has long been employed and proven therapeutic in Maya medicine.³¹ The question remains, however, how do jokes and humour work within the narrative structure? In addition to asserting the perspective that cancer films need not always be poignant and dark, it still leaves us with questions: Who is the assumed audience?; Who and what are we laughing at?; and At what point should we find the films and their stories about suffering funny?

A Humorous Anecdote

The 2007 Hong Kong film, *2 Become 1*, can be regarded as just another mainstream romance comedy about a woman with breast cancer and a man who has erectile dysfunction (thereby sexualising both diseases). It is the only film I have researched to date that allows the protagonist to find true love *because* of her disease and, most notably, it is a comedy with a happy ending. Breast cancer is not a funny

²⁹ Fred Rosner, “Therapeutic Efficacy of Laughter in Medicine,” *Cancer Investigation* (Vol. 20, No. 3, 2002) p. 434.

³⁰ William B. Streat, “Laughter Prescription,” *Canadian Family Physician* (Vol. 55, October 2009) p. 966.

³¹ See Michael J. Balick, “The Role of Laughter in Traditional Medicine and its Relevance to the Clinical Setting: Healing with Ha!” *Alternative Therapies* (Vol. 9, No. 4, 2003) pp. 88-91.

matter. It involves very sensitive relationships among breast cancer as a disease, breasts as dismembered parts of the female body, and gender politics. Although breast cancer is a specific kind of gendered story that warrants a unique cinematic narrative, I find *2 Become 1* useful because it has managed to make both the woman's breast and cancer "funny" enough to elicit genuine laughter from the audience.

The film is an adaptation of an autopathography entitled *Mourning for the Breast (Ai Dao Ru Fang)* (*Mourning* hereafter), written by the prolific Hong Kong author, XiXi, about her own experience with breast cancer.³² *Mourning* is the author's story of how cancer, from the moment of diagnosis to recuperation after treatment, tormented both her body and mind. More importantly, it is about how she pieces together some sense and meaning from her experience by drawing from her rich reservoir of knowledge on a broad range of subjects – including women's breasts, cancer, Chinese Medicine, biomedicine, literature, and art. *Mourning* is more than a personal journal about being ill. It is a book that impersonalises the cancer experience while maintaining the first person point of view. The filmic adaptation, in contrast, is a transition/translation from a serious literary work to a commercial genre and while the first person perspective is retained, there is a marked difference between the two.

In *2 Become 1*, breast cancer is subject to the imagination and interpretation of men. The protagonist, Bingo (played by Miriam Yeung), is a thirty-something, career-minded single woman. At the end of a night out with her friends, she goes home with an attractive man named Vincent (played by Richie Ren), whom she picks up at the bar. As he is undressing her, he feels a lump in her breast and "kills the moment" by telling her it could be a tumour. Bingo, however, thinks that Vincent is

³² *Mourning for the Breast* is a direct translation from its original Chinese title 《哀悼乳房》. No pronoun is used to specify whose breast the author is mourning (see XiXi [西西]'s *Ai Dao Ru Fang* [哀悼乳房]. Taipei Shi: Hong Fan Shu Dian [台北市：模範書店], 1992).

simply making a poor excuse to change his mind about sleeping with her. She worries that her breasts are not big enough or that he simply does not find her attractive, so she kicks him out of her flat in a fit of anger without giving him a chance to explain himself. Vincent persistently urges Bingo to see a doctor for a check-up the following day. She eventually does and is told that there is indeed a lump in her breast. At the clinic, the doctor explains to Bingo in details (in the presence of her friend and in front of the audience) the possibility that the tumour might turn malignant and outlines the treatment options, which depend on the size and nature of the cancerous growth. Bingo faints on receiving the news. Afterwards, she goes through the stages of denial and depression and, similar to many people living in a modern society where biomedicine is the dominant medical system, she seeks alternative treatment from a non-orthodox source (an ex-boyfriend she is still waiting for but who is now a con man). She is subsequently asked to drink some unknown herbal medicine and apply a dark mixture that is supposed to be made of expensive herbs to her breast to shrink the tumour. With Vincent's help, she finally realises that it was all a sham, but not until the last moment when she is handing the quack and the ex-boyfriend a large amount of cash. With her hopes shattered (here, the audience is led to believe that it is largely due to her broken heart rather than the failure to find a miracle cure for her cancer), Bingo resorts to attempting suicide. After several failed suicide attempts and with the full support and encouragement of Vincent, Bingo is finally able to come to terms with the loss of her ex-boyfriend and the seriousness of her illness. Towards the end of the film, the audience learns that Bingo will have the mastectomy recommended by her physician. The film ends with Bingo shopping with her daughter for a bra many years later, which implies that she is able to enjoy her blossoming career and a fruitful and fulfilling relationship with Vincent – living like a normal woman in a modern fairytale ever since her surgery.

The film is easily criticised for not adhering to XiXi's original story and for stealing the "aura" of literature and turning it into a commercial "vulgarity" where a woman's breast and its disease become the source of (male) jokes. It was also a failure at the local box-office, yet its inherent imperfections deserve a closer look. Much like the *Bucket List*, *2 Become 1* was made for the entertainment of a mass audience. The storyline and intention of *2 Become 1* actually resemble those of the early cancer films made by the ACSS, which focused on educating the public. In an interview, director Wing-cheong Law confessed that the film only aimed to serve as a messenger of positive attitudes for women faced with cancer, and that cancer need not mean a death sentence.³³ In many ways, the film is not unlike the self-help material available in bookstores.

Furthermore, the film's target audience is assumed to be women in their early teens to middle-age, which is made obvious by the casting of Miriam Yeung as the protagonist. To the local Hong Kong Chinese audience, Yeung is Bingo and Bingo is Yeung. Yeung, as an actress, does not appear to have presumed a different persona for this role. Known commonly and endearingly in Hong Kong as "a woman with a big laugh" (Da Xiao Gu Por),³⁴ Yeung started her career as a singer more than a decade before. She has also starred in a number of blockbuster love comedies. The (female) audience can easily identify with Yeung's ordinariness. A registered nurse before her singing career took off, Yeung has since become a professional performer and is known for the fact that she excels in neither singing, nor acting. Thus, her popularity springs from the lack of distance between her and the audience. She is as the characters she portrays on-screen: imperfect and not particularly talented, but in relation to the largely female audience, *one of them*. In fact, the same year the film

³³ Source: <http://www.cinespot.com/cinterview14.html> (last accessed 22 Feb 2010).

³⁴ This is a direct translation from the Chinese phrase, 大笑姑婆, which describes women who are funny and like to laugh heartily.

was released, Yeung was made the ambassador for the Hong Kong Breast Cancer Fund. As a result, the focus of this film is not necessarily on cancer (and its cinematic significations); rather, it is on the (female) body with cancer, a career with cancer, a love relationship with cancer, and perhaps most importantly – Yeung, a pop icon and someone whom the audience identifies with, having cancer. Rather than using the hospital or the clinic as the main site of cancer, the site expands to include the office, the bed, and even the spa where Bingo and her friends spend their leisure time. These also become the sites of laughter and humour.

Throughout the film, we laugh at the situations Bingo finds herself in. For instance, at one point she must ask her boss for a few days off from work to go to Szechuan (a province in China) to see a miracle healer. We find the elaborate excuses she fabricates to hide the fact that she has cancer pathetic, but funny. We laugh at the way she joins the elderly at the park for Qigong practice. We even laugh at her successive but frivolous suicide attempts. None of these elements are directly about cancer, but unlike Carter and Edward in *The Bucket List*, we laugh at this woman who challenges cancer in her own self-deceptive way. Bingo is smart, funny, and competent at her job, but not without her own stupidity (e.g., she falls for a con man). However, unlike the early ACSS movies, her stupidity does not stem from her avoiding the topic of breast cancer, but from her clumsy way of dealing with the everyday life she still must face *as* a breast cancer patient. For example, how does she tell her boss that she needs to take a prolonged sick leave? How does she tell her family about her illness (in fact, she never gets the chance to share her prognosis with her family due to everyone's busy schedule and the daily drama that is characteristic of sharing a living space)? On another occasion, when she is about to kill herself by

burning charcoal in her bedroom,³⁵ she changes her mind after glancing at the newspaper she is using to fan the charcoal. In effect, she is saved by a report printed in the corner of the newspaper about how another woman's decision to commit suicide in her flat ruined its re-sale value. The next scene shows Bingo dragging the charcoal and the container to her office late at night to finish her business there. Unfortunately, the smoke from the charcoal sets off the fire alarm and, threatened by the unsympathetic security guard (who is afraid of losing his job), Bingo leaves, devastated as the audience laughs at how she must resign herself to the redundant, mundaneness of life (hers and others'), even in the face of cancer.

As these examples show, situating the site of humour in the spaces where one works and lives serves as a reminder to the audience that cancer does not remove one from the confines of one's living space and day-to-day relationships – even when one is dying. Cancer is not an ellipsis in this case because it is openly uttered by the characters. It is more similar to a comma, which pauses an unfinished sentence while its intended direction remains undeterred. This is also significantly different from *The Bucket List's* use of unfamiliar, even foreign spaces to discover new meaning and expand possibilities. *2 Become 1* insists that cancer does not abruptly change one's life or remove it from the original on-going life narrative. It does not necessarily open us to a new world that has never been experienced. It also does not provide us with new, special insight or wisdom, as in the case of Carter and Edward. Bingo is grounded in her reality where cancer is both a physical and figurative lump in her life.

Breast cancer is potentially a fatal disease that has claimed many lives. It is also a disease of the female body. What makes people most uncomfortable is when a woman's dismembered body becomes the fodder for jokes when her body (and

³⁵ Burning charcoal in a closed room to induce carbon monoxide poisoning is a very common way for one to commit suicide in Hong Kong because it is not easily discovered by other family members who are living together in the same flat.

emotions) are at their most vulnerable. However, throughout the film, jokes are made about the size of Bingo's breasts and, to the chagrin of most feminists, this romance comedy is actually built around the double meaning of the film's English and Chinese titles – *2 Become 1* and *Born to be a Pair (Tian Sheng Yi Dui)*.³⁶ The official English title implies both the consequence of a mastectomy and two people becoming one couple/entity. The Chinese title is more problematic. Literally, it can be taken to suggest a woman who was born to have a pair of breasts, which implies that one-breasted women are not “natural”). Adding to the controversy it is the fact that Vincent suffers from a form of impotence ever since the night Bingo kicks him out. “Pairing” these two people means relegating breast cancer to a merely sexual disease of the female body, in that the woman is de-sexualised, and considering the breast as something that is exclusively for attracting the opposite sex. However, Bingo, breast cancer patient or not, is already objectified as a character on the cinematic screen. First, this is the story of her body and her illness. Second, when Bingo's breast cancer is projected on-screen, her story, including her body and herself – as portrayed by Yeung – become the object of gaze and desire. One example that stands out is in the opening scene when she suspects that Vincent is turned off by her because of the size of her breasts. The audience is also invited to look at a close-up shot of her breasts to scrutinise them along with Vincent. Another social criticism of this film is based in the suggestion that breast cancer is used as a “punishment” for women who do not confine to traditional roles. For example, after her diagnosis, Bingo is portrayed as “changed” for the better – no longer as aggressive and much more considerate of others. Breast cancer forces Bingo to seek medical treatment and put to rest her strong, independent character as if they were partially responsible for the disease. Furthermore, as a behaviour therapist, Vincent not only makes Bingo a better person

³⁶ Translated from the Chinese title 《天生一對》.

and a better patient, but also a better lover. Hong Kong film critic Ka-ming Chan remarks on this form of symbolic female castration:

In *2 Become 1*, the death of a breast needs no mourning. It is because no matter how mutilated the female body and her emotions are, a man (even if he is impotent) is still the best medicine, for everything is back under control in his presence.³⁷

While some jokes about breast cancer are considered disempowering, particularly those that make the women's breasts the object of male humour, Cynthia Ryan argues that breast cancer humour is subversive when women can talk about their experience in the public domain and create their own jokes. Specifically, the use of humour can address women's need to cope and critique the discourse of the female body, as Ryan explains:

Within this discourse of comedy, there exists a balance of humour that on the one hand, reinforces the need to 'cope' with female ideals when one's breasts are removed, and on the other, rejects altogether the current methods for addressing and treating the disease.³⁸

Quoting another feminist scholar, Nancy Walker, Ryan also suggests that breast cancer humour can sometimes be unintelligible to those who have never experienced cancer because "humour is one of the expressions of the codes by which a group operates".³⁹ I extend Ryan's argument to include the ways in which humour is used and appreciated in cancer films. If the topics and forms of these jokes are to express what it feels like to have cancer (whether as patient or observer), we must also bear in mind that there is an index of each operating group's values and taboos.

This brings us back to the general criticism of mainstream cancer culture.

Both *The Bucket List* and *2 Become 1* share the same fall-back of normalising the disease in a way that tames righteous anger ("Why me?") in favour of a more

³⁷ Original text in Chinese: "一個乳房死，就是如《天生一對》所言根本不用哀悼，因為女性的胴體與感情即使如何被生吞活剝，一個男人(即使如何無能)總可以是上方良藥，控制重組。" Source: <http://www.filmcritics.org.hk> (Accessed 22 Feb 2010).

³⁸ Cynthia A. Ryan, "Reclaiming the Body: The Subversive Possibilities of Breast Cancer Humour," *Humor* (Vol. 10, No. 2, 1997) p. 196.

³⁹ *Ibid*, p. 203.

“appropriate” attitude that acknowledges optimism and positive thinking as the only way to heal from cancer because it causes the least amount of suffering in others.

Writing about her own breast cancer experience, feminist author Barbara Ehrenreich describes her rage at the lack of (political) activism:

In the mainstream of breast-cancer culture, one finds very little anger, no mention of possible environment causes, few complaints about the fact that, in all but the more advanced, metastasized cases, it is the “treatment,” not the disease, that cause illness and pain.

Likewise:

The effect of this relentless brightsiding is to transform breast cancer into a rite of passage – not an injustice or a tragedy to rail against, but a normal marker in life cycle, like menopause or graying hair. Everything in mainstream breast-cancer culture serves, no doubt inadvertently, to tame and normalize the disease: the diagnosis may be disastrous, but there are those cunning pink rhinestone angel pins to buy and races to train for. Even the heavy traffic in personal narratives and practical tips, which I found so useful, bears an implicit acceptance of the disease and the current barbarous approaches to its treatment: you can get so busy comparing attractive head scarves that you forget to question a form of treatment that temporarily renders you both bald and immuno-incompetent.⁴⁰

Mainstream cancer films do not politicise or create an expansive community with an ethical responsibility to change such misdirection. And the question of normalising is especially problematic in cancer. However, Diane Price Herndl, a fellow breast cancer patient, follows Ehrenreich’s argument and reflects on what is so bad about normalising breast cancer:

My question, though, has to do with the whole problem of the normal. Is illness not a normal part of living? Should we not be teaching people that expectations of bodily perfection and control of our physical destinies are unrealistic?⁴¹

Illness is a normal part of living, but the normalisation of cancer is particularly complicated by cultural assumptions about what physical qualities in a person’s appearance are “normal”. Ehrenreich’s argument seems to identify mainstream

⁴⁰ Barbara Ehrenreich, “Welcome to Cancerland,” *Harper’s* (November, 2001) p. 49.

⁴¹ Diane Price Herndl, “Our Breasts, Our Selves: Identity, Community, and Ethics in Cancer Autobiographies,” *Signs: Journal of Women in Culture and Society* (Vol. 32, No. 1, 2006) p. 239.

culture as the main influence on this lack of different (angry) voices to do justice to the “tragedy” of breast cancer, yet no such “duty” to challenge and protest is required of people who have bowel cancer or leukaemia. Does that mean that such cancers are caused by something we did to ourselves, such that we cannot blame anyone else? Why breast cancer is singled out from other types of cancer is not within the scope of this chapter, but I do wonder what choices there are between the violent treatments and long suffering of this disease. Coming to terms with one’s own mortality is never easy, the wound is painful, and there is no one standard way to heal – nor is there one way (mainstream or not) to cope. Some patients choose to remain silent and strive to put it out of their minds. Bingo undergoes a radical surgery as a form of treatment that should not be interpreted as an act of heroism (to normalise the treatment), but rather her decision to look forward towards what is in store for her in her future – whether it is Vincent, a new lease on life, or even motherhood – despite her scars. There should be more than one form of healthy embodiment, and while there are those who choose to endure the treatment for the sake of overcoming the disease at all costs, there are also those who challenge the medical analysis and cultural representation of the disease.

This chapter has shown that popular, mainstream cancer films can be considered to be merely “normalising” a deadly disease by perpetuating images of cancer patients and constructing a very homogenised emotional direction. However, as Ehrenreich also admits, mainstream culture’s habit of sugar-coating has proven a useful coping tool, such that the emotional turmoil of cancer can be broken down into a few humorous anecdotes.

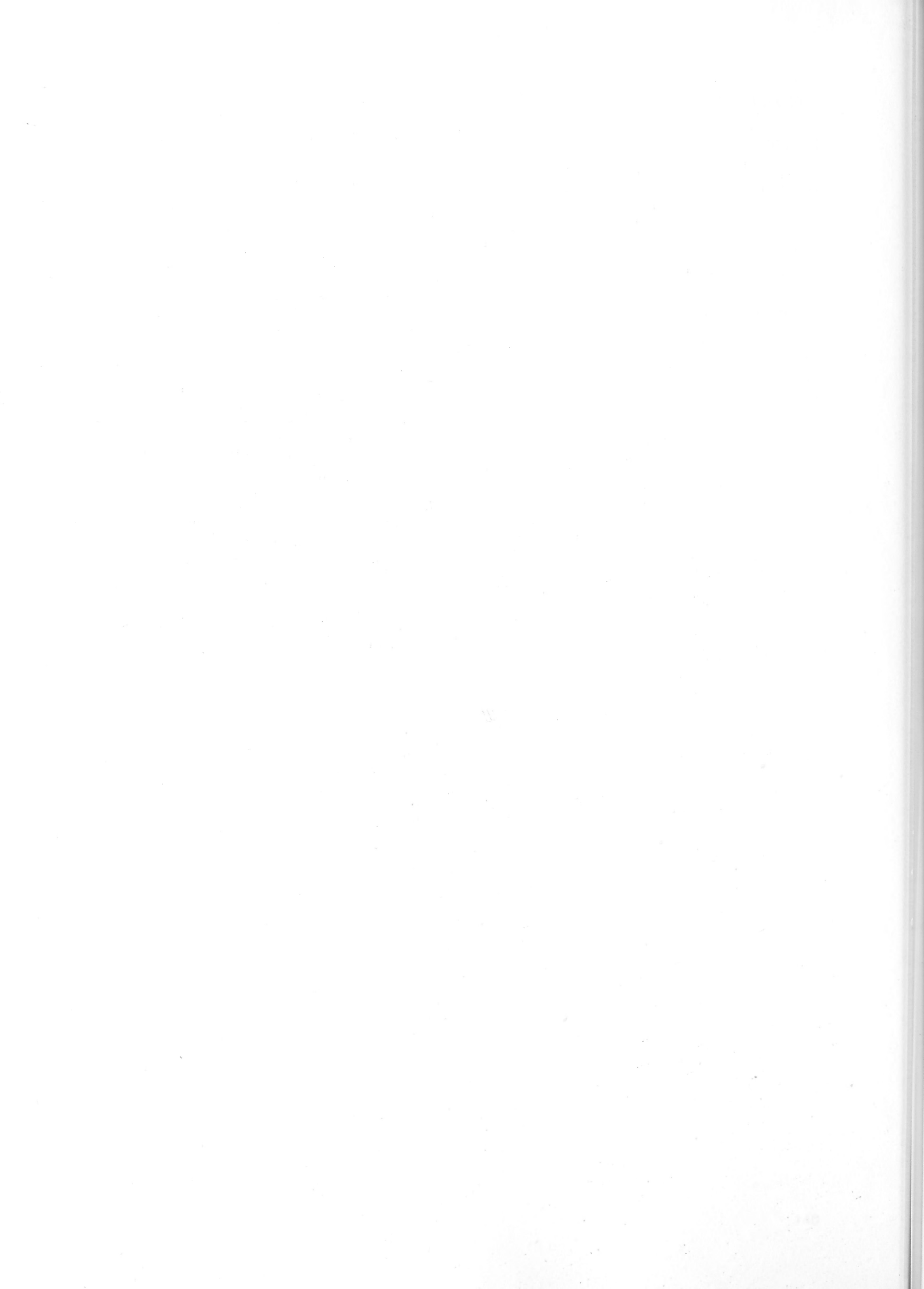
Chapter Four - Cancer, Healing and the Body

While the previous chapters have focused on the
beginning of the journey of how space and time shape the
of cancer into the stories of healing. As the text
concerned with the spatial story of cancer and the
differences which allow us to understand the
photography that points out the structures
and hidden realities of the body and the
really distinct and different ways of
by the patient and the doctor, and the
creative cancer reality of the body.

SECTION II:

THE SPATIAL STORIES OF CANCER

The following text discusses the spatial stories of cancer
and how they are shaped by the body and the
form is born to the body and the
interconnectedness of the body and the
and the body and the
However, the text
describes the body
to point to the body
and the body.
a subject which is
the body and the
and the body and the
Therefore, to know about cancer, one must be
enter into an immensity that we can only attempt to feel.



Chapter Four – Cancer Realities Out of *The Spare Room*

While the previous chapters have focused on what is *not* there, this chapter begins a new section on how space tells stories, particularly, how it turns the stories of cancer into the stories of healing. As the first chapter of this section, it is concerned with the spatial story of cancer and how cancer can “take place” at different sites, which allows its *othered* realities to emerge. Although literature and photography can point out the ghostliness of the cancer experience, there are always other hidden realities marked by ambiguities and contradictions that make the cancer reality elusive as it unfolds and changes. By elusive, I specifically mean what is lived by the patient but has somehow eluded representation. We can liken searching for the elusive cancer reality to using our hands to feel for something immense and multifaceted while blindfolded. Through touch, we can only feel one part of what we are touching and cannot know what the full object is like. Hence, its full shape and form is bound to elude us (as in the parable of the blind men and the elephant). Interestingly, there is also no way of grasping its full immensity even if we remove our blindfolds because there are limits to our senses and our capacity to feel. However, the more people there are to touch its different parts in different places and describe to the group how it feels, the better our chance of gathering enough evidence to paint a full picture. This is one way to understand cancer – as something unknown and multidimensional; something ambiguous and without closure. It is not cancer as a subject within biomedicine that is immense, it is the knowledge required to know it, the lives it takes to experience it (those of patients and observers), and the sides/facades/voices – hidden and manifested – from which it is comprised. Therefore, to know about cancer, one must go beyond (scientific) representation and enter into an immenseness that we can only attempt to feel as it unfolds. As such, we

might gain access to the *othered* realities that do not fit within the main, manifested reality.

In this chapter, I use Australian author Helen Garner's fictional work, *The Spare Room*, as an illustration of a spatial story of cancer from which the aforementioned realities emerge. I argue that both *The Spare Room* as a narrative and the spare room depicted in the novel are sites for the elusive ambiguities that create the story of cancer. Published in 2008, *The Spare Room* is not the first literary attempt to address the subject of cancer from the perspective of an observer/care-taker,¹ nor does it use cancer as a symbolic disease to talk about something else, as its many predecessors did. By focusing on two women's respective struggle with cancer – Nicola, the patient suffering from an un-named cancer and Helen, her best friend and care-taker/observer of Nicola's cancer – *The Spare Room* is one of the few literary works that sheds some light on the multiple realities of cancer. As such, I begin this chapter by discussing how the mainstream popular representation of what having cancer looks like can sometimes lead us to even more unanswerable questions about what can and cannot be shown in regard to cancer; specifically, what is considered "legitimate" reality and what is hidden. I argue that allegory can be a way of knowing something that is still in the process of unfolding. Drawing on the works of Emily Potter and of John Law respectively, I propose that we can understand the "mysteries" of cancer in the same way, in which this particular poetic practice foregrounds ambiguity and points to what is beyond the manifested reality, which provides access to the *othered* reality of cancer.

Next, I focus on the spare room described in the novel and examine its role as a site of heterogeneous cancer realities. I show how it reconfigures cancer

¹ Recently published fictions about cancer include: Mary Alice Monroe's *Time is a River* (2008), Marisa de los Santos' *Belong to Me* (2008), Matt Marinovich's *Strange Skies* (2007), Ray Kluun's *Love Life* (2007), and Ellen Sussman's *On a Night Like This* (2005).

realities into what Garner herself calls the “material world”, and how cancer “materialises” to the observer at different stages. Although we are led to understand the spare room as just an upbeat place for friendship, it quickly becomes obvious that it also serves as a refuge for the dying cancer patient (Nicola) to suffer in private and survive the rigours and pain of both her treatment, and her cancer. To the observer (Helen), the spare room where her friend is staying also becomes the place where she witnesses the “spread” of cancer from the room through the rest of the house. Helen realises that she, too, is a “victim” of cancer because she is cohabiting with Nicola in this “cancerous” space she calls home. Later in the book, the presence of cancer is gradually replaced by the shadow of death, and Helen senses that dying is more than what she had initially expected from Nicola’s visit.

I then refer to John Law and science studies scholar Annemarie Mol’s development of the Actor-network Theory to further elaborate on how cancer is not simply described and lived by the patient (as can be seen in most personal autobiographies and biographies) or necessarily and rationally represented by scientific narrative. Actor-network theory is a general social theory on technoscience, and it has its origins in an attempt to understand science and technology. More importantly, the theory allows for the creation of larger and stronger networks that include both human and non-human actors, blurring the boundary between human/non-human, as Rolland Munro writes, ““Actor-network theory rejects that solace of humanism, 'man's mastery of technology'”.² What it means is that both human and non-human have interests that need to be accommodated in their actions and interactions in order to achieve a common purpose. Although ANT is usually applied to the study of science and technology, I find it useful in expanding the

² Rolland Munro, “Actor-Network Theory,” *The SAGE Handbook of Power*. Ed. Stewart R. Clegg and Mark Haugard (London: SAGE Publications Ltd, 2009), p. 125.

property of healing from human as agents to objects as agents. In fact, according to Law and Mol's theory, representations of cancer can be material – woven into a web of interactions with objects. Without needing to be sentimental, objects that are symbolically connected to our everyday life help create a network of movement that enables social interactions between humans and humans, and humans and objects. Drawing from various examples in the text, I note the many ways stories of cancer are expressed via objects in our everyday lives and illustrate how the *othered* realities of cancer can emerge from these various channels through hope and resignation about dying.

Once we begin to pay attention to these *othered* realities, they become the obvious smudges/noises that obscure what is being told in the main narrative, which renders the state of cancer realities “messy”. Paradoxically, the messiness of cancer not only makes cancer more “present” in its own right, but also we get to see how the disease *take place* at different sites. For example, cancer *takes place* in Nicola's body, in the spare room, and in the social spaces cohabited by the two women and other objects. Cancer realities become “alive and dynamic” as two people come to terms with one cancer by reflecting on its different realities (hidden and manifested) through their respective struggles. Hence, if we centre our focus on the space of the house in which the spare room is located, we realise that it houses a wide spectrum of cancer realities without mapping a one-way trip to healing (signified by a forward-looking mind-set) or inviting rumination about a past laden with cancer-causing factors. These realities, which are not static and ready to be captured by representation, are therefore elusive.

Allegories and Othered Realities

To see how these elusive realities emerge, we return to the popular representation of cancer and focus on the popular images of what a person with cancer looks like. We know that cancer is a “wasting disease” because the aberrant cells are dividing uncontrollably and creating tissue masses that eventually invade organs and destroy normal tissue. Dying, more than death itself, defines this illness. Asking what a person with cancer looks like is equivalent to asking what a person being destroyed or “eaten away” by cancer looks like. The concept of “wasting” and dying also suggests that the body is in transition, which puts images of cancer in the category of the abject and the non-representable. Stacey addressed the difficulty of representing a person with cancer when she juxtaposed two pictures of herself before and after the diagnosis of her teratoma, post-chemotherapy:

[...] the first, I look healthy, but I have cancer; in the second, I look ill, but I do not have cancer. Neither shows me what I am looking for: the visible signs of the disease.³

“Having cancer” cannot be reified to be seen, but it can be replaced by the now popular image of the “aftermath” of cancer – baldness covered by a hat or scarf. Because there is no other physical sign more visible, hairlessness has now become a prominent cultural symbol of what a cancer patient ravaged by the disease looks like and is used to articulate what cannot be directly spoken.

³ Jackie Stacey, *Teratologies: A Cultural Study of Cancer* (London and New York: Routledge, 1997), pp. 138-9.



Caption: The bald truth - Felicity Huffman unveils her new look for season four of the hit show, *Desperate Housewives*, in which her character, Lynette Scavo, battles breast cancer.⁴

The cultural meaning of cancer baldness has become very different from what female baldness used to mean. This new baldness that results from chemotherapy announces to the public that the patient is not ashamed to tell others that she is a cancer patient and is willing to take on the role of warrior. For example, the above image is of the breast cancer patient played by actress Felicity Huffman in the popular American TV drama, *Desperate Housewives* (Season 4). Images such as this conveniently convey the clichéd message to the viewer that it is okay to have cancer because it will not destroy you and, most importantly, because you are not alone. These popular images are not actually telling us what *dying* looks like, however, and as Stacey noted, no matter how positively a cancer warrior is portrayed, she and her cancer can only be materialised within the discourses of the abnormal and the grotesque because “they are tales of monsters and marvels that pervade the popular imaginary of cancer subculture”.⁵ Thus, even though the *Desperate Housewives* character is a successful,

⁴ Source: <http://www.thisislondon.co.uk/showbiz/article-23414494-desperate-housewives-lynette-battles-against-cancer.do> (Accessed 15 October 2011).

⁵ Stacey, *Teratologies*, p. 10.

independent woman, it only takes one look for us to know that she is “different” from other women.

Hairlessness; pale, waxy skin tone; and sunken eyes form the typical (popular) cancer image that we are most familiar with. However, the use of these images to disguise the truth about the disease or to serve other political purposes (such as the Look Good... Feel Better® education programme that teaches women how to “look healthy” by using cosmetic products)⁶ is roundly criticised as highly gendered and critics argue that such use does no good in terms of giving meaning to suffering. Instead, these images regulate and authorise what is a normal/abnormal, healthy/sick, or beautiful/ugly within the feminine body. It has also been argued that just as there are mouth sores and other post-surgical complications present in a cancerous body, besides hair loss, knowledge about cancer cannot and should not be limited to visual images portraying what is only visible to the eyes. Writing about the Look Good...Feel Better® programme, Catherine Phillips warns that materialising an illness such as cancer using popular discourse and visual images of the (female) body runs the risk of mistaking the physical as what defines health and normalcy, in addition to seeing the body as exclusively physical at the expense of other knowledges about cancer.⁷ One may rightly accuse these popular images of perpetuating and naturalising the feminisation of cancer, but they are nonetheless part of our collective knowledge of what having cancer looks like. Admittedly, the proliferation of such images of what cancer looks like (as embodied by a female

⁶ The Look Good... Feel Better® programme was started in the US in 1989 by the Cosmetic, Toiletry, and Fragrance Association and the National Cosmetology Association. This programme, connected to hospitals and cancer care centres, claims that if cancer patients can receive the assistance they need to look good, then their self-esteem will help them approach their disease and treatment with greater confidence. The programme was extended into Australia, Canada, New Zealand, the UK, Germany, and Denmark throughout the 1990s and later, into the Netherlands, France, Sweden, and Ireland in the 2000s (see Catherine Phillips, “Images, Femininity and Cancer: an Analysis of an International Patient Education Programme,” *Health (London)* (Vol. 13, No. 1, 2009) pp. 67-85.)

⁷ Phillips, “Images, Femininity and Cancer,” pp. 81-2.

patient) highlights the fact that there is a disconnection between the images and experiences of illness. The opposite is also true, however, because although these images cannot directly capture the cancer experience, this failure does not prevent cancer from seeping into images (or our own imagination) unconsciously, to be expressed as a parapraxis. That is to say, what makes the image of a bald Felicity Huffman convincing as a cancer patient goes beyond the fact that it is a good imitation of what a cancer patient looks like in real life, it addresses all the *othered* realities that are not seen as well.

To make sense of these unconscious slips (and their effect on the *othered* reality), I draw on Emily Potter's understanding of the notion of climate change, which is also changing and unfolding to such a degree that it can only be grasped through scientific prediction, to suggest that cancer can be understood in a similar way. We cannot definitively know whether today's changing climate is a normal, natural phenomenon or the result of greenhouse gas and carbon emissions from fossil fuel use and cars. What we have are scientific predictions of what might happen, but in reality these predictions are also subject to change based on a constant flow of new data. Much like our anxiety over the current state of the global environment and ecology, our knowledge about cancer is based on materially/scientifically grounded "data" (a form of scientific narrative and representation). The authority of these scientific narratives engenders the common public discourse with the use of illustrative graphs and figures representing research findings in an effort to present itself as a source of irrefutable truth. These illustrations bear no ambiguities in their making. To know about cancer, we must rely on scientific discourse for a taste of truth, but what we know is also constantly changing. For instance, not knowing what causes this disease or why some people have it while others do not – even if they are smokers and have a relatively unhealthy lifestyle – makes it difficult to articulate or

meaningfully represent the incoherence of an unfolding event such as cancer. If cancer is unique to each of us, how can we assemble this uniqueness to paint a full picture? Given the fact that the cancer experience is simultaneously personal, physical, and emotional, we also rely on artistic representation to speak on behalf of the patient about the cancer experience. However, artistic representations are irrelevant to what is portrayed by science, both in terms of content and function, because they may already depict two unrelated realities of cancer. Considering all of these different forms of texts, discourse, and information, how do we construct a coherent reality? Is it even possible to accurately represent things as elusive as cancer and climate change? To answer these questions, we must turn away from the manifested reality to see what lies outside – through an allegory.

Traditionally, allegory is perceived as a poetic practice that conveys meanings other than the literal. However, according to Walter Benjamin's understanding, allegories arise from "an apprehension of the world as no longer permanent, as passing out of being: a sense of its transitoriness, an intimation of mortality, or a conviction".⁸ Allegory can also be taken as a technique for transforming things into signs. In his passage on Charles Baudelaire's poetry, for instance, Benjamin writes that the vanishing Paris is allegorically captured by the poet. The "woman" in Baudelaire's poems embraces both the decadent life of a prostitute on the streets of Paris and the lure of an attractive woman caught in the gaze of the *flaneur* in a fleeting moment of love at last sight. In another example, Baudelaire uses the image of a white swan juxtaposed with the modernised city's dark side. The memory of "Andromache" is to grieve for the fleeting love that can only happen once on the streets of Paris because Paris is "dying" and being replaced by a new life of

⁸ Bainard Cowan, "Walter Benjamin's Theory of Allegory," *New German Critique* (No. 22, Special Issue on Modernism, 1981) p. 110.

modernity. Benjamin explained the relationship between the *flâneur* and this elusive state in the following way:

In Baudelaire Paris becomes for the first time a subject of lyric poetry. This poetry is not regional art; rather, the gaze of the *flâneur*, whose mode of life still surrounds the approaching desolation of city life with a propitiatory luster. The *flâneur* is still on the threshold, of the city as of the bourgeois class. Neither has yet engulfed him; in neither is he at home. He seeks refuge in the crowd [...] The crowd is the veil through which the familiar city lures the *flâneur* like a phantasmagoria. In it the city now a landscape, now a room.⁹

Thus, we use allegories to foreground ambiguity (situating ourselves on the threshold) or the elusive before it settles down on either side of the dialectics. According to Benjamin, “ambiguity is the pictorial image of dialectics”.¹⁰ As we follow the gaze of the *flâneur* from his position “on the threshold”, we see neither the old nor the new Paris, but both simultaneously – caught in the act of vanishing.

In her paper on the difficulties of representing climate change, Potter examines how one can know climate change, given the fact that the very notion of “change” relies on scientific predictions and other things that are beyond our grasp. Potter suggests bringing artistic and scientific representation together in an effort to “capture” and “convey” these changes to arrive at a truth about the unfolding world:

Signs of change obsess us and we look to science for orientation through these. Poetic representation is valued as a tool of communication and inspiration – to educate, warn and motivate response.¹¹

We need both artistic and scientific representations to orient and motivate our responses. This is where allegory can bring the two representations together. According to Potter, allegory is “an active agent, it takes part in shaping what we

⁹ Walter Benjamin, *Reflections: Essays, Aphorisms, Autobiographical Writings*, ed. Peter Demetz, trans. Edmund Jephcott (New York: Schocken Books, 1978) p. 156 (Italics original).

¹⁰ *Ibid.*, p. 157.

¹¹ Emily Potter, “Climate Change and the Problem of Representation,” *Australian Humanities Review* (Issue 46, May 2009) p. 69.

know – a tool that enables us to read ‘between the lines’ of any apparent reality”.¹²

In his argument, which stated that realities are produced by a “generative flux of forces” in an unformed and unstructured world, Law suggested that one way of knowing something that is still unfolding is to look beyond the manifested reality being represented and allow ambiguity to point to other traces of the “out there”.¹³ He claimed that the use of allegories offers an unsettled way of investigating the world and its “out-there-ness”.

Cancer is not the streets of Paris, and we are not *flaneurs* strolling in the kingdom of the ill in any sense, but we can see that representing cancer and its experience allegorically through the interplay of dialectics allows us to paint a picture of the elusive or what cannot otherwise be expressed in a temporally linear narrative. In *The Spare Room*, if we think allegorically, the spare room can be considered as a “threshold” from which the narrator can gaze at what lies between dying and hope. It also provides a vantage point from which the reader can overlook the different realities that have been veiled by the dominant manifested reality. The spare room is what Potter referred to as a “discursive trace” materialising the reality that cannot otherwise be represented.

A Room For Healing?

The Spare Room is a fictional work about a three-week interaction between two women, Helen and Nicola. The narrator, Helen, is a grandmother and a writer. Nicola, Helen’s old friend, is suffering from a cancer that has spread to her bones and liver. Nicola comes to Helen’s home to stay in her spare room while she undergoes a series of alternative treatments, involving intravenous ascorbic acid and

¹² Potter, “Climate Change and the Problem of Representation,” *Ibid.*, pp. 76-7.

¹³ John Law, *After Method: Mess in Social Science Research* (London and New York: Routledge, 2004) p. 6.

an ozone sauna at a nearby facility called the Theodore Institute. Although Nicola appears to be in greater pain each time she comes back from her treatments, she insists on religiously keeping all of her appointments at the Institute. In the meantime, Helen finds herself caught in a moral dilemma. Should she confront Nicola with what she really thinks about what she considers quackery? Should she urge Nicola to simply accept the fact that she is dying and that massive doses of Vitamin C will not send the cancer “on the run”, or should she assume the role of palliative care nurse and be a matron for her dying friend? As the story unfolds, Helen’s narration also seems to have a difficult time controlling the rising surge of anger and fear – not only towards Nicola’s treatments at the Institute, but also towards her friend’s increasingly stubborn denial of her mortality despite the pain she is suffering. As the days wear on, Helen realises that she is the one who is unable to handle Nicola’s illness (and its physical manifestation), which is omnipresent in Helen’s own house.

As I mentioned earlier, the spare room in Helen’s house is not set up as a private refuge for Nicola. It is not a personal healing space. In fact, it contains all of the sickness, frustration, and helplessness that come with cancer. These moments are what have eluded representation in the many examples of illness literature that have burgeoned in the past few decades. This is especially true for biographies and autobiographies that focus on the cancer experience by chronicling a personal, spiritual, or healing journey. In such accounts, even though healing is admittedly part of the reality of an illness experience, it is little more than a matter of looking back, inspired by the wisdom of retrospection. Healing, in these personal accounts, is the gradual construction of a mental forte to distance the illness from one’s life. However, in her novel, Garner turns healing into something horrible, messy, and even painful by including feelings that do not typically belong within the mental

space of healing. This begins with the two women's different perceptions of dying (of cancer). Accompanying Nicola's refusal to make any simple effort to relieve her pain is Helen's awareness of the "out-of-place-ness" of her own anger. She feels her anger should not be displayed or even sensed in her own house. This anger is directed at her friend, but even more at the fact that her house should not be a place for (her friend's) dying. Just as there has never been a "right" place for pain, there is certainly no right place for the emotions attached to dying, because its abject state must be immediately "removed" or brought to a halt, which makes Helen as helpless as Nicola:

What was all this anger? I needed to be kinder to her. Dying was frightening. But it was easier to imagine being tender when I had a packet of slow-release morphine capsules in my bag (p. 74).

We may rightly wonder whether the morphine is for Helen or for Nicola's pain, because it is obvious that Helen's spare room houses one ambiguity of the cancer reality: there is neither a clear-cut state of health, nor a clear-cut state of death, which renders everything out-of-place and all emotions inexpressible. To Helen, facing death and dying – eye-to-eye – is frightening because it is the abjected "Other". This is made worse when the one who is dying refuses to lie down quietly and prepare herself for death (It is because if death is life that becomes inanimate, then dying is naturally imagined as life being slowly taken away). Thus, Helen needs the morphine capsules to make sure that Nicola's pain, dying, and all of the other frightening aspects of cancer remain under her control. It becomes Helen's duty to put dying in its right place – a place where it is safely secured by the effects of the morphine and the physical reality of cancer and dying – such that dying of cancer is once again confined within the "in-place-ness" of the spare room and Nicola's body.

As we can see in *The Spare Room*, when the dying patient (Nicola) refuses to resign to death and instead fills the spare room with pain and suffering, we realise that dying is not, and cannot be, confined to Nicola's body. Dying becomes the "out there" that cannot be directly addressed. It requires the *othered* voices to manifest itself in another (verbal) form. These *othered* voices can come from "non-linguistic verbal forms" capable of enacting the "non-coherent reality" of dying.⁸ As John Law has stated, realities are "non-coherent" because they are not necessarily singular or what we assume to be causally related. As such, the events that construct a reality are complex "because they necessarily exceed our capacity to know them".⁹ Because these realities are non-coherent in nature and composed of both manifested reality and what is "out-there", they sometimes exist outside of words. In other words, what is elusive about the reality of cancer refers not only to what is inaccessible to language but what is not entirely expressible. Indeed, stripped of all sentimental scenes and among dialogue that remains terse, but emotional, what is not spoken between Helen and Nicola is expressed mostly in anger, which is an attempt to bring the *othered* reality (the horror of dying) back into the verbal realm. For example, after surviving yet another night of rigour from the Vitamin C injections, Helen finds Nicola in the living room and notes that she has returned to her usual, good-humoured self – once again in denial. In Helen's eyes, this is a source of suppressed anger in the house:

⁸ John Law, *After Method: Mess in Social Science Research* (London and New York: Routledge, 2004) pp. 7, 92-3 (Italics original).

⁹ *Ibid.* p. 6.

She [Nicola] tilted her head, stretched her lips, and there it was again, plastered across her face like latex – the smile. The last of my self-control gave way. ‘Get that grin off your face. Get it off, or I’ll wipe it off for you.’

...

‘Everyone’s angry, everyone,’ scared, I shouted. ‘You’re angry and scared. But you won’t admit it. You want to keep up the masquerade, so you dump your shit on me. I’m sick with it. I can’t breathe’ (p. 137-8).

On another occasion, when the two women are having morning tea with another friend, Peggy, Nicola recounts her recent experience with the treatments:

‘So,’ said Peggy at last. ‘How’s it all going, over there?’

‘Well,’ Nicola began, leaning forward with a smile so glassy it tinkled. ‘It’s all going brilliantly. Helen’s a wonderfully severe matron. But we’ve had to get hold of some morphine the last few days. You see, at the Theodore Institute, which is marvelous, they give me a certain intravenous vitamin C treatment every second day.’

She was settling in. Irritated, I tipped my head back and took a proper look at the roses. Quite a few of them were already drying up and drooping. The secateurs lay near me on the windowsill. I grabbed them and made a few furtive passes at the blossoms within reach.

‘It does knock one around somewhat,’ Nicola went on, ‘and I sometimes come home a wee bit under the weather.’

...

‘Of course I know I’ll always come through it unscathed. I know it’s only the vitamin C savaging the tumours and driving them out. But,’ she said with a gay laugh, ‘to my utter astonishment, and to my shame for being so pathetically selfish, I was absolutely and totally unaware that to poor Hel it was a horrendous spectacle.’

Anger becomes a mode of conveying the unspeakable (such as fear and love) and putting it in (a linguistic) place. In the above excerpt, Nicola’s inexplicable facial expression and her suffering now have a place within some sort of channel because anger is something that can be expressed with such forcefulness that it cannot be contained. In fact, anger is often expressed much like something that has spilled over. Anger is physical, and its expression is embodied (e.g., the description of anger is often connected with body heat or associated with fluid in the body, as in “anger is

starting to surge”).¹⁰ This explains why “cooling off” is the first step in dealing with anger. Likewise, it is from between this flow of “bodily heat and fluid” that these *othered* realities “leak”, which leads to more questions: Why do we say things to hurt the ones we care for most?; and When a patient battles against cancer with the most positive thinking, does she appear as irrational as Nicola does to Helen in the eyes of her care-takers/loved ones?

In the representation of cancer and of cancer patients discussed at the beginning of this chapter, we see that there are many more things that the main narrative does not say, or fails to capture. Similarly, throughout *The Spare Room* there are other non-verbal narratives that convey *othered* realities that are different from the ones manifested by Helen and Nicola. To find traces of what materialises between the lines, our job is to look for a connection where the out-there-nesses converge without trying to understand them as one coherent entity. To achieve this, we must place ourselves at the threshold and be aware of the presence of cancer and how it affects daily interactions, not only between humans, but also between humans and objects. We can then begin to assemble realities that cannot be captured by the main narrative strand.

Cancer in the Spare Room

If a home is traditionally a space for nurturing the sick back to health, Garner’s spare room invites us to consider the other realities involved. Consider the spare room as a place for cancer as an antagonist, a place for friendship between two females, a place for coping with dying and death, and even as an allegory for hope. This can be seen in the way Helen prepares the room and the thoughtfulness she puts

¹⁰ See Zoltán Kövecses’s “Anger: Its Language, Conceptualization, and Physiology in the Light of Cultural Evidence” in John R. Taylor and Robert E. MacLaury (Eds.) *Language and the Cognitive Construal of the World* (Berlin and New York: Mouton de Gruyter, 1995) pp. 181-196.

into both Nicola and her cancer. The novel begins by describing Helen's preparation of the spare room. She swivels the bed to sit on a North-South axis to align the sleeper with the planet's positive energy flow. She takes out all of the pillows in the house because she is not sure whether Nicola would like a flat pillow or a bulky one. She opens the window to let the fresh air drift in and makes a mental note to put some potted plants by the window. She wonders if the floor is too cold for the bare feet of her friend. She even imagines whether it is appropriate to place a mirror in the room:

Would she want to look at herself? ... She might take it the wrong way if her room lacked a mirror. I found one I'd bought in an Asian import shop at Barkly Square and never used: a tall, narrow, unframed rectangle of glass, its back still equipped top and bottom with strips of double-sided adhesive tape. I selected a discreet spot for it, just inside the door of her room, and pressed it firmly against the plaster (p. 43).

At first glance, this arrangement of objects to make the spare room more comfortable for Nicola makes use of spatial arrangement to transform the spare room into a place of comfort and familiarity reminiscent of a domestic space. However, it is also precisely how the presence of cancer determines the arrangement of objects in a space. For instance, the "energy" that is flowing in and the promise of potted plants, which imply liveliness and health, must be arranged to counteract/balance the physical manifestation of cancer, to the extent that Helen worries about what might complement "skin that has turned yellowish" (p. 1). Such preparation is not so much for healing as it is to offer relief from the presence of cancer; specifically, using a set of objects to offset what the disease may bring forth and thus altering the meaning of the original set of objects. The spare room is designed to suppress the physical aspect of the cancer reality from emerging, but the question remains: Which realities can be kept hidden and which will eventually spill over?

Furthermore, the spare room serves as the threshold from which we can glimpse at the cancer realities comprised of both the bravery to endure the torment

of physical suffering and fear of death. We see that Nicola is simply doing what she feels she must, including enduring the physical pain on a daily basis in an effort to survive. From her perspective, as long as she is doing something she is not passively awaiting death's arrival. Helen, as the observer, sees only the useless nature of Nicola's fight and she is afraid that the sham at the Theodore Institute will only serve to torture her friend to the very last breath of her life. These two perspectives, which constitute different cancer realities, prompt (unanswered) questions about what places like the Theodore Institute really mean to people dying of cancer, in addition to issues such as the governmental regulation of alternative treatment clinics. Such questions include: Is the Institute really the cause of Nicola's worsening condition, or is it a result of her cancer?; Which pain is more unbearable – that of bone cancer or that of not doing anything to keep from dying?; How much fighting against death is enough?; and When is the right time to stop fighting? None of these questions have definite, satisfying answers, but posing and pondering them can reveal other "invisible" realities that might have otherwise remained suppressed in language.

At times, we must also acknowledge that when we are talking about cancer, we are also talking about other things. In the case of Nicola and Helen, they may be simultaneously dealing with the effectiveness of unorthodox cancer treatments, pain management, palliative care, friendship, hope, and many more. Cancer, in other words, is also what Law referred to as a "moving target that cannot be held still for a focused study". In Law and Singleton's investigation of how local hospital trusts handled patients suffering from alcoholic liver disease, Law remarked that what they were trying to study had become a "shape-shifting target":

We had been commissioned to study the treatment of alcoholic liver disease, ALD as we called it. But it didn't take long before we found that we were talking about other phenomena that had something to do with ALD but weren't the same. For instance in some interviews we found that we were talking about liver disease (in general, without the alcohol). Or we found that we were talking about alcoholic cirrhosis. Or, again, about alcohol abuse. Or (and this is not necessarily the same thing) about alcoholism. Or, indeed, sometimes about the overall quality of life in relation to substances including alcohol.¹¹

In a similar vein, cancer is something that continually slips out of focus. The more we try to find out what it is, the more we end up talking about other things.

Likewise, in the novel, the more Helen tries to make sense of what her eyes can see – the fact that her friend is dying and yet still subjecting herself to “harmful” treatments – the more she finds herself seeking answers from “outside”. For example, unable to cope with the sight of Nicola's pain and physical suffering (because it should have its own private, personal, hidden space), Helen naturally feels compelled to re-align facts and reality to make sense of it. She begins to look for an answer in what she sees; anything that might prove that the underqualified “doctors” at the Institute have been brainwashing Nicola with lies and profiting from giving a dying person false hopes. The first time Helen goes to the Institute with Nicola, she is put off by the unavailability of Professor Theodore – a sign that she takes as unprofessionalism. Her distrust worsens during the compulsory presentation by the doctor who is there, Dr Tuckey, whose obvious typo in the title slide, “Cancer and It's Treatment”, is something that she hopes Nicola will see and come to the same conclusion as hers. Nicola just keeps on smiling and focusing intensely on what Dr Tuckey is saying about how high doses of Vitamin C will kill the remaining tumours in her body.

The second time that she is at the Institute, Helen finds Nicola being submerged in the ozone sauna. The question of who runs this Institute looms large

¹¹ John Law, “Making a Mess with Method,” version of 19th January, 2006, available at <http://www.heterogeneities.net/publications/Law2006MakingaMesswithMethod.pdf>, downloaded on 22 Oct, 2010, p. 4.

in Helen's mind because neither Dr Tuckey nor Professor Theodore is overseeing Nicola's unconventional treatment. The third time she goes to the Institute she finds the usual receptionist, Collette, absent and replaced by an "unsmiling middle-aged stranger with an Eastern European accent. His white coat and slow, almost tranquillised movements lent him an air of authority lacking in the endearing but twitty Collette" (p. 50-1). This time Helen is able to voice her complaints/suspicious about the treatments to someone "with authority", but she is ignored. To add insult to injury, Nicola even urges the self-identified specialist to "carry on" (p. 52). That night, Helen suspects that the intravenous Vitamin C has brutalised Nicola's spine because Nicola cannot hold herself erect. However, despite her suffering, Nicola, fighting like a true warrior, refuses to give up. Eventually, Helen files a formal complaint with the Health Services Commission (although the reader is not told whether the complaint is followed up), which raises more questions: Who has the right to complain to an institution? and What, exactly, warrants complaint – something that does not effectively cure cancer, is not scientific enough, or feeds the false hopes of dying patients?

The Spare Room: Movement and Objects

The spare room in the novel actually exceeds the materiality of a spare room by serving as an allegory for the messiness of cancer. It is a place where illness, the struggle, and death – all part of living well – are not rendered hidden or invisible by the main narrative. And more importantly, it allows the elusive cancer realities to emerge via movement. It is because cancer involves not just the core individuals, but a whole invisible network of actors that are in the background, as defined by Annemarie Mol:

Events are made to happen by several people and lots of thing. Words participate, too. Paperwork. Rooms, buildings. The insurance system. And endless list of heterogeneous elements that can either be highlighted or left in the background, depending on the character and purpose of the description.¹²

According to Mol, the traditional understanding of illness and disease has always considered them objects of biomedicine. In contrast, a sociological understanding places disease in the world of meaning, which is culturally specific and can be opened to historical and social scientific investigations. Mol thus proposed a third step in understanding disease and illness; to allow objects to come into being through the practices with which they are manipulated. Thus, by foregrounding “practicalities, materialities, *events* ... ‘disease’ becomes a part of what is done in practice”.¹³

Objects (such as cancer) need not be the focus of different people’s perspectives and can be perceived as participants within an event that facilitate the unravelling of the folded realities that are usually hidden from the main narrative. If cancer is also part of the participating agent, it is communicative and interactive, which means that this time, the voices of the others can be heard because there will no longer be one, single, central perspective focusing on a single object. Therefore, by challenging the centrality of humanness in realising reality, Mol’s theoretical reorientation of human/non-human relations enable us to shift from considering the cancer experience as a determinate thing that humans represent, to considering it as something that is mediated by a network of actions and movements involved in the practicalities and materialities of cancer.

The Spare Room is composed of descriptions of numerous trips between Helen’s home and the Theodore Institute, in addition to other places whenever Nicola

¹² Annemarie Mol, *The Body Multiple: Ontology in Medical Practice* (Durham and London: Duke University Press, 2002), p. 25-6.

¹³ *Ibid.*, p. 13.

feels good enough to step outside the house. The spare room is not merely the space in which Helen passively observes how Nicola suffers daily in her fight for her life against cancer. Likewise, the novel is more than a description of what Helen, as the narrator, sees. It records Helen's participation in interactions with cancer and the ill body of Nicola as she navigates the city. As we follow Helen's narrative "gaze", we also notice that Nicola's cancer changes her behaviour and that of Helen in her role as an observer. Foregrounding what they inadvertently do during their day-to-day excursions and negotiations of movements, we come to understand cancer as an *event* that is unfolding. Thus, *The Spare Room* presents a physical reality of cancer that is not simply described and lived by the patient or the observer, but can also be a material web woven from our interactions and communications with objects. It is through the materiality of things that various effects and outcomes are produced. On her interview on ABC Radio National, Garner admitted that she was conscious of how these various objects in the material world also constitute part of the world/reality of illness:

I always like to work with the material world a lot. I've never been much good at thinking or arguing abstractly. I don't feel comfortable unless I've got a lot of objects on the page, and they seem to do an awful lot of work if you can arrange them into the right configuration. They carry a huge amount of energy and meaning, and it's just a matter of respecting them really.¹⁴

The description of how cancer has afflicted Nicola is told through the shapes, sounds, and mise-en-scène constructed through Garner's literary representation. Here is one example:

Towards six o'clock a key was laboriously inserted into the front door, and a silhouette came shuffling down the hall. Her [Nicola's] shoulders were bowed, her knees were sagging; her head was thrust forward on a neck that was almost horizontal. Oh, what had they done to her? I

¹⁴ "Helen Garner's Creative Uncertainties," *The Book Show*, ABC Radio National (Mar 12 2009). See complete transcript at <http://www.abc.net.au/radionational/programs/bookshow/helen-garners-return-to-fiction-with-the-spare-room/3159836> (last accessed 25 July 2010).

jumped to my feet. But as she came into the light of the kitchen I saw on her face again that terrible smile, the grimace that said, *Do not ask me any questions* (p. 55, emphasis in original).

This portrayal of cancer as the uncanny “silhouette” is manifested through the sagging knees in the shadows, which are in contrast to what Helen sees in the light: the horrifying smile so incongruent to the picture that makes it even more grotesque. Through this interplay between light and shadow and the incongruence of actions and appearances, realities are assembled via the plain objects: the hallway that transmits the sound of the shuffling and the light that never fails to make the heart sink – these are part of the realities that reveal the paradox of fighting and hoping within this brutal and heart-breaking disease.

Dying and hope are the last set of suppressed realities in *The Spare Room*, which makes cancer more “present” in its own right by letting us see all its faces, shapes and forms. The cancer that is omnipresent in Helen’s house cannot be made invisible, despite its effort to that effect. In contrast, the very private and personal space becomes a room in which Nicola physically suffers every time she returns from her treatments; a place where she adds her own sickness (in various bodily forms that include sweating and soiling the bed sheets and waking up and groaning from the rigours and pain of cancer) to the cleanliness of the space that was once a symbol of health and normalcy. Almost immediately, Helen cleans them up and freshly prepares the space. Thus, the room no longer represents loving care, but rather the place where Nicola’s disease manifests itself despite Helen’s effort in masquerading it (which is also Helen’s own way of fighting Nicola’s cancer). Neither is Helen the sole witness. The mirror tells us more about this point. Tall, narrow, and unframed, it is a reflection of Helen’s mental image of what Nicola would look like. The adhesive tape should not have been used to support the mirror because the assumption is made that it requires more and, as expected, the mirror

falls and shatters in the middle of the night before Nicola is due to arrive. The mirror (the object) is also a witness that (fore)tells of a dying friend coming to visit and a weight that might be too much to bear. The pieces of shattered glass, which reflect the different realities in irregular, jagged shapes capable of piercing an aching heart, must be cleaned up before the final moment arrives.

In addition, the pillows and bed sheets are frequent material witnesses that participate in Nicola's illness, with Helen constantly making the bed and fluffing the pillows:

[W]hen I woke up at six and walked into the kitchen to raise the blinds I almost tripped over her [Nicola]: she was crouching on the floor with her arms round her knees, making tiny rocking movements. Her bed, when I went to look, was a twisted mess of wet sheets.

'I didn't want to wake you,' she said. 'God. I'm so sick of this pain.'

Together, not speaking, just working, we got her up and washed and dried and onto the couch. I threw open the windows and tucked a rug around her. Her face was white (p. 66).

Likewise, in the end stages of Nicola's experience, when she has to take morphine to get through her pain:

She was sweating hugely from her head and neck. Her pillow was a puddle. I changed the bedding again and again. It was labour. It was *Let me turn the mattress*. It was *This*, and *No, you must drink*, and *What else can I bring you?* And *Lie down now*, and *Go back to sleep*. It was hard and I was tired, but rarely had I felt so useful (p. 175).

Thus, cancer moves along and walks through the everydayness of Helen and Nicola's lives, manifesting as small individual events within the folded realities. By moving, it also leaves trails that can be used as collective evidence of the *othered* realities that mark its out-there-ness, which has no place in representation. The reader interacts with different objects described in the novel and is confronted by the lurking presence of cancer in the form of questions, which are compounded by its messiness. The mirror (Does it break so that she can be spared the pain of her

reflection, and what does cancer's reflection look like?); the wet shoes (Why does Nicola wear them when it is clear that they are bad for her, considering that if she slips, her cancer-devoured C7 vertebra might collapse and leave her a quadriplegic); the broken eggs (Why do they break while Nicola and Helen are discussing the issue of hospice?); the bedroom (Does its transformation into a hospice room imply that there is no way to undo or revert the effects of cancer?); the ozone sauna room (How useful is this treatment? What makes it appealing to Nicola but repulsive to Helen? Does it have any psychological effect?); the garden (How much longer do Nicola and Helen have to share the joy of friendship in this space?); the soiled bedsheets (What has cancer done to Nicola's body and her dignity?); the pain (What is it that is inscribed on Nicola's physical appearance that is affecting Helen?); drugs (Why does the morphine seem to empower Helen in dealing with her dying friend, who at first refused to take it?); and many others including the lift, the sidewalks, and the decorative flowers – the list goes on.

Even if we can say that the Theodore Institute and the spare room are locations where cancer takes place, it is actually the irrelevant objects that connect the ambiguities (those that appear but are not fully manifested) to reveal the truth about the realities of cancer. The spare room simultaneously becomes a room (to look out of) and a landscape (to look at from afar) transformed by a series of movements and actions. Rather than understanding cancer as an object of multiple interpretations (e.g., from such perspectives as biomedicine, Chinese medicine, bio-engineers, holistic healing, patients, observers, and academics) we view it as an event practiced by both humans and objects. Cancer is formed not only from shared or fragmented perspectives, but with objects, actions and movement that piece together different realities that connect the dots to complete the story of *The Spare*

Room. In this case, objects do not just serve as memory triggers in one's everyday life; they also become predictions and tell-tale signs.

Heartache and the Final Response

Garner admitted in an interview that deciding to give the narrator/protagonist (Helen) her own name has become one of the public's common concerns with the work because readers want to know whether it was based on a true story:

People seemed to have this crazy obsession with pinning me against the wall to find out if these things were based on real stories, or had I got the right to call it a novel, and it occurred to me ... well, actually it occurred to someone else who pointed this out to me, that this is another way of avoiding getting close to what the book is about, death. Let's not talk about the death stuff, let's just talk about the mode in which it's written, or we can make a lot of clatter and noise over here and the death part can just stay over there in the dark and we won't have to worry about it. Even intellectually grasping that doesn't help, because the fact that we're all going to die is just sort of intolerable on some terribly profound and unreachable level.¹⁵

To talk about death and dying is also to talk about hope and healing. Garner crafts a fictional cancer reality using the spare room, the Theodore Institute, the garden, the homes of friends, and other objects, to spin a web of different and contesting cancer realities. It is not exclusively a story of hoping, healing, or dying, but rather a fusion of all three. In fact, *The Spare Room* can be taken as a fictional space in which one can safely encounter all of this disease's incongruent and contradictory realities to understand the underlying truth about cancer as dying pain is transformed into healing pain. To the readers and Helen as narrator, it is easier to see Nicola simply accept her fate – to “look around her, take a deep breath, and say, ‘All right. I am going to die. I bow to it. Now I will live the rest of my life in truth’” (p. 95). It would be so much more agreeable and gracious because it would render the “truth” about dying much *less* complex as a commonly accepted heroic way of putting

¹⁵ “Helen Garner’s Return to Fiction with *The Spare Room*,” ABC Radio National’s *The Book Show* (Jan 13, 2009). See complete transcript at <http://www.abc.net.au/rn/bookshow/stories/2009/2452524.htm> (last accessed, 19 July 2010).

disease and death within a natural, casual explanation. However, when that moment finally arrives; when Nicola, after taking the morphine capsules and waiting for them to take effect, finally says to Helen:

‘I don’t think I’ll do the vitamin C anymore,’ she murmured. ‘It’s too hard. I’m too weak for it, at the moment.’

Helen’s response is:

This was what I had been fighting for, but my heart began to ache (p. 158).

Heartache is the final allegory for the unspeakable, ambiguous state of cancer throughout Garner’s work. It is one thing to deny death and be always on the defence; it is another to resign to it. However, once the struggle has ceased and there is no dialectical pull between the two characters, there are no words to describe the final stillness that has grown in the core and heartache is the closest way to describe what is left to be felt. When Helen finally comes to realise that everything is too late and that even anger is rendered wordless, that death is finally taking over, there is only one thing left to say: “Death was in my house. Its rules pushed new life away with terrible force. I longed for the children next door, their small, determined bodies through which vitality surged” (pp. 80-1). Finally, towards the end of the novel, the description of a magic performance that Helen and Nicola attended together describes her heartache and paints the final, “messy” realities of cancer caught between dying and hoping.

The young magician had turned to Nicola and said: “There are many ways to make a thing disappear. Do you want me to show you the fast way or the slow way?” Nicola had only “smiled, and nodded many times, but did not reply” (p. 148). After the performance, the women were walking to the car and talking about their respective favourite acts. Nicola said:

'I love all of it,' she said. 'But Hel. My absolute best bit was at the very start, when he looked right at me and said, "There are many ways to make a thing disappear."'

I said nothing. She kept her eyes down. I heard her stifle a gasp of pain as the car thumped over the railway tracks and crossed the Moonee Ponds Creek in the dark (pp. 151-2).

This scene is not translating the elusive state of cancer into textual form, but it can be read as an allegory of hope for the dying. Magic is not "real", but optical illusions and misdirection do let us see what we want to see, and that becomes real as it draws us affectively, magically, into another reality – not as cold fact, information, or knowledge, but as transformative recognition. When this is placed in contrast with all-too-rational science, our attention is drawn to the very human need for innovative treatments – a spell that allows us to "believe" in magic from time to time, be it a miracle pill or a new cure for cancer, such that our mind can trick us into seeing what is impossible, despite what we think we know. The allegory of dying is not to bring it to presence, for it cannot be acknowledged if we are to "keep the possibility of alterative meanings always in play".¹⁶

To summarise, *The Spare Room* is an allegory for the indistinct, complex, and elusive states of the cancer reality that are lived and experienced by those who come into contact with the disease. It contains traces of the impact of cancer, which are scattered around, unattended, and can only be gathered/manifested between the lines. Beginning in the spare room and extending throughout the rest of the house, these traces and all of their inherent conflicts and contradictions are assembled as a (messy) cancerous site and we respond via actions and movements to register the presence of the *Other* – what we are unable to cope with – by staging a linguistic distance between it and ourselves. This renders the protagonist/narrator's home a site of struggle between suffering and comfort; love and anger; hope and hopelessness; and

¹⁶ Potter, "Climate Change and the Problem of Representation," p. 77.

bravery and weakness. In the end, when confronted with all of the *othered* realities, we have nothing to rely on but our own imagination to cope and heal.

Chapter Five – Place, Space, and the Architecture of Healing

Although biomedicine is still effective in treating a lot of the diseases known to mankind, the solution to a medical problem no longer comes exclusively in medicinal form. In fact, some solutions involve an interdisciplinary prescription that takes us to different places and spaces in search of healing experiences, such as those generated via the creative use of spatial design. In this chapter, I examine the places and spaces of healing with a particular focus on two cancer-care centres located in North America and the UK, respectively. By analysing the social and spatial functions of these centres alongside their interior and architectural design, I show how they affect the cancer experiences and healing of those who use them.

At present, there are many places where people who are affected by cancer can go for social support. The idea behind this type of cancer-support or -care centre is for people to share their experiences – what they do and how they interact with one another and their stories. This raises a question; specifically, do people interact with their surroundings as well, such that the ambience and even the space at large affect these interactions? I begin this chapter by attempting to answer this question by examining the relationships among place, space, and healing. Although the “vast emptiness” of nature is typically considered a healing space because it is away from our day-to-day lives and home is the place where people are usually nurtured back to health, when it comes to healing from a disease such as cancer, we require other places and spaces to address our non-biomedical needs. This need for space is not limited to the patient; friends and family members or anyone affected by cancer, directly or indirectly, should be able to share their experiences, too. Through sharing and interacting with one another, rather than being “removed” from the illness,

healing can be established as situated within the cancer experience so that the healing journey can begin.

Next, I discuss the function of Gilda's Club, a group of cancer-care centres in North America and examine its social function as a place. Human geographer Yi-fu Tuan's insight about space and place informs our understanding of the relationship between these two elements. Furthering Tuan's argument that places define spaces;¹ I argue that functions also define places. Hence, a place such as a Gilda's Club centre is neither a home, nor a hospital, but rather what Troy Glover and Diana Parry describe as a "third place".² As a "third place" – a social place that exists away from private places such as homes (first places) and institutions such as hospitals (second places) – a Gilda's Club centre serves as a place of initial contact where people can start their journey of healing. Moreover, it is a place where healing is experienced in a positive way (by acknowledging cancer's presence) without having to keep the disease out of sight.

This unique function of making its users/visitors feel at home is a crucial ingredient in the process of demedicalisation within a healing space, especially for institutions such as hospitals. A demedicalised space must resist the hegemony of medical practice and the hierarchy between patients and healthcare professionals through a continuous and creative process. Demedicalisation involves the use of colour, the placement of objects, and the arrangement of various places within the space to create a therapeutic ambiance favourable to the users. Because ambiance cannot be linguistically defined, demedicalisation is also an important step in one's efforts to interact with the space (of healing) in an effective way. A healing space

¹ Yi-fu Tuan, *Space and Place: The Perspective of Experience* (Minneapolis: University of Minnesota Press, 1977).

² Troy D. Glover and Diana C. Parry, "A Third Place in Everyday Lives of People Living with Cancer: Functions of Gilda's Club of Greater Toronto," *Health and Place* (Vol. 15, No. 1, 2009).

requires that we interact not just with other humans (such as at a Gilda's Club centre), but also with objects and the materiality and immateriality within the space. I use Maggie's Centre, a chain of cancer-care centres located mostly in Scotland, to illustrate how this works.

Maggie's Centres are different from other similar support centres because each Maggie's Centre is unique in its architectural design and each is built by a world-famous architect, such as Frank Gehry, Kisho Kurokawa, or David Page and Brian Park from Page and Park Architects. For this reason, every single Maggie's Centre is an individual architectural work of art – both a space and an artefact that bears a healing quality. Basing my analysis on Bruno Latour and John Law's actor-network theory as introduced in the previous chapter, I first show how a Maggie's Centre allows our spatial experience to become a constant interaction with the illness experience and how this, in turn, forms a kind of multi-directional communication between space, place, and object that contributes to a spatiality that is fluid and mutable within its spatial boundary. Finally, I highlight how a Maggie's Centre is also a healing artefact on its own. Constructed in the larger urban landscape and usually built adjacent to a local hospital, the studied Centre's physical presence is characteristically incongruent with the surrounding area. And it is precisely because of its incongruence that enables us to see how different spaces (both inside and outside) can merge and interact with one another through their exteriority and interiority. Hence, as an artefact, the Centre "changes" shape as it moves, adapts, expands, merges, opens, and shifts according to how one's experience with cancer interacts with its materiality and immateriality; exteriority and interiority.

Place, Space, and Healing

From the medicinal use of humour and laughter that dates back to the ancient Maya to the use of acupuncture needles, healing can be understood as a function of a specific encounter between healer, patient, and the materials involved such as jokes, needles, or the atmosphere in the setting where the healing takes place. Given this, it is not one material alone that heals. For example, it is not one particular needle that cures a certain disease during an acupuncture treatment or, in the case of herbal medicine there is not one herb that works universally against a flu virus. Healing requires a mix of heterogeneous healing agents that is specific to each encounter. Healing, space, and place are intrinsically inseparable because all are needed for healing to take place. Therefore, healing is not simply an action performed by the healer, it is also an event that interacts closely with the geography and environment of the “who”, “where”, and “when”.

Of all the healing places and spaces, the natural landscape is deemed the most fundamental to any healing environment. According to the hierarchical concept of the biblical order of creation, humans are at the very top, followed by animals, and then plants. Nature, animals and plants included, is therefore viewed as being at our disposal to cultivate and civilise as we choose. The word “nature” in the English language has always been understood to mean “the way the physical world is”. Nature is a phenomenon that has nothing to do with human creations, but throughout history it has adopted many different meanings as our lifestyles change. These days, natural space is visualised as being far away from one’s work- and home-life – somewhere to escape to. The dualism that separates work and leisure implies that the work-place is where stress is, whereas nature is where one can truly relax. This turns nature into a safe haven from all of modern society’s maladies and problems because it is perceived as the opposite of

human creation. As such, whether the goal is to heal from cancer or from a broken heart, nature is the space that is most often believed to possess restorative power.³ Many people find that spending a weekend in the countryside or simply being outdoors to “get away from it all” is refreshing and hence, therapeutic. The beauty and aesthetic pleasure found in nature, such as a tranquil lake or a pastoral landscape, is partially the result of its remoteness from the pollution and stresses of city environments. The natural environment is, and has always been, considered in the light of abstract geometrics without any gathering of things. It is not a place filled by people, social activities, and objects. Most notably, it is without tangible physical boundaries. The pleasure generated by this emptiness and boundlessness has become an ideology that extols the healing capacity of nature as an open space into which people escape to experience the immensity and freedom by embodying their feelings, images, and thoughts in its intangibility. In this sense, nature symbolises a sense of freedom – particularly freedom from meaning (there is no symbolic meaning ascribed to a mountain, for example).

On the other end of the spectrum, we have biomedicine, which works against pathogens, bacteria, and viruses and uses surgery to remove things from the body that are deemed harmful to its normal functions. Were pathogens found outside the body, biomedicine could still work perfectly well, even without the presence of symptoms or a patient. Rather than *taking place*, biomedicine requires its own well-circumscribed site from which to contextualise and perform healing. One of these places, which is specially built and designed for this purpose, is the hospital. However, we must bear in mind that a hospital is an institutional edifice created solely for the purpose of eliminating disease. Hospitals are positioned *against* disease. Perhaps this is why they are the first thing that comes to mind in relation to diagnoses

³ For example, see Stephen Kaplan's "The Restorative Benefits of Nature: Toward an Integrative Framework," *Journal of Environmental Psychology* (Vol. 15, No. 3, 1995), pp. 169-182.

and treatment. To call a hospital simply a “space”, however, is not entirely correct because within the space of a hospital patients can still choose between a public or a private room, and there are additional places that patients must go at different stages in their illness that exist within the hospital, such as the Outpatient Unit for chemotherapy, the Radiology Department for radiotherapy, and the Oncology Department for other follow-up examinations. Each of these places is supervised by a team of specialists within a highly specialised area while the hospital is defined by many different locations and places according to their functions. In other words, the space of the hospital is made up of these various functional and specialised areas.

I discuss the space of the hospital later in this chapter in relation to the concept of demedicalisation, but I must note here that because diseases such as cancer, multiple sclerosis, and Alzheimer’s are becoming more complex – well beyond a singular, biological problem that only concerns the patient – experts are now calling for a unique type of healing place capable of addressing the non-biomedical needs of patients with these evolving diseases. The need for such a healing place implies that it is not only the patients who must live with these illnesses, but also family members and loved ones. This explains the increasing demand for alternative and complementary treatment centres, acupuncture clinics, and cancer support groups, in addition to the hospitals, to attend to the various medical and emotional needs of cancer patients. It also sheds light on the fact that the treatment of cancer does not simply end after chemo- and/or radiotherapy. For cancer survivors and their loved ones, once the course of medical treatments is finished the real healing begins. Healing in this sense implies making the patient feel whole again – post-surgery, post-cancer – by way of a holistic experience.

Gilda's Club as a Healing Place

Perhaps to some people living with cancer, seeking a place that offers social, emotional, and communal support is the first step in this journey of healing, which involves pausing, and seeking others in the community, depending on the stage of their illness. "Place" is often considered a social construct, imbued with the deep meanings that individuals attribute to its objects and settings based on social experiences and interactions, whereas "space" is usually considered a mere empty container.⁴ Regarding the relationships among space, place, and the human experience, Tuan provides the first insight when he notes: "Place is a type of object. Place and objects define space, giving it a geometric personality."⁵ In his book chapter entitled "Intimate Experience of Places", Tuan explains that a person who is ill is more likely to identify the familiarity of his home as an intimate, nurturing place and that this sense of home as a place where the sick can be nursed back to health is unique to human beings among primates.⁶ Therefore, based on Tuan's concept, place is a pause in the movement within a given space; specifically, the location where a person rests and is cared for. The opportunity to be "in touch" with other human beings and establish a home attachment is essential to healing, and Tuan adds: "One can no more deliberately design such places than one can, with any guarantee of success, the occasions of genuine exchange."⁷

With this background in mind, we turn to Gilda's Club and examine how such a place is used and perceived by people with cancer and how they, in turn, give it

⁴ French philosopher, Henri Lefebvre, argues that our idea of an abstract, scientific space emerges from Cartesian logic. Using scientific understanding to unravel the mystery of the natural world has led to the notion of space as a Euclidean geometric space "which philosophical thought has treated as an 'absolute,' and hence a space (or a representation of space) long used as a space of *reference*" (see Henri Lefebvre, *The Production of Space*, trans. Donald Nicholson-Smith, Oxford: Blackwell, 1991, p. 285 (Original emphasis)).

⁵ Yi-fu Tuan, *Space and Place*, p. 17.

⁶ *Ibid.*

⁷ *Ibid.*

meaning. The Gilda's Club centres are places where people living with cancer can seek social and emotional support from others sharing similar experiences. Named in memory of Gilda Radner, an American comedienne and actress who died of ovarian cancer in 1980, the first Gilda's Club was co-founded in 1991 by Joanna Bull, Radner's cancer psychotherapist, and Gene Wilder, Radner's spouse. Located all over North America, each Gilda's Club centre serves as a community meeting place. According to its website, the collective mission of the Gilda's Club centres is to provide inclusive communities for anyone who has been affected by cancer – from patients and those who have lost loved ones to the disease, to those who have known cancer survivors. These cancer support communities were also intended to complement medical treatment,⁸ which implies that these centres go beyond medical treatment to heal patients in a holistic manner.

The simple addition of a few designs here and there to project the presence of “health” is not enough for a facility to be considered complementary to medical treatment. It must actually incorporate new functions and meanings as it is being used. In an article examining the everyday life of people living with cancer in relation to the function of a social space, Glover and Parry argue that Gilda's Club centres can be taken as a “third place” for cancer post-patients. “Third place” is an original term coined by Ray Oldenburg that refers to an informal public gathering place that is away from one's home (first place) and the work-place (second place).⁹ A Gilda's Club centre as a “third place” indicates that it has successfully integrated therapeutic functions into a social space that is neither in a domestic setting, such as a home, nor in an institutional setting, such as a hospital. In their study, Glover and Parry interviewed Gilda's Club members to determine how they felt about the centres

⁸ Source: <http://www.gildasclubtoronto.org/> (Last accessed: 16 September 2010).

⁹ Ray Oldenburg, *The Great Good Place: Cafes, Coffee Shops, Bookstores, Bars, Hair Salons and Other Hangouts at the Heart of a Community* (Washington DC, Marlowe and Company, 1999).

and what they had to offer. Most of the participants replied that it could be a constant struggle to share their emotions with their family members, and that their local Gilda's Club centre was a place to make friends with others who shared similar experiences and could empathise with their stories of cancer.

People with cancer are often torn between wishing to spare their loved ones from the worries (especially about recurrence) and not believing that family members are capable of understanding their fear and anxiety. Such concerns show that living with post-operation cancer is no longer a medical problem because worries about such things as hair loss, recurrence, and body image (particularly for women who have undergone a mastectomy) are part of their daily lives.¹⁰ Glover and Parry conclude that a "third place" such as a Gilda's Club centres has a significant and positive impact on people living with cancer because having a "home away from home" and a "home away from the hospital" means that they can escape from the stressors in either of those places and enjoy a sense of community. What Glover and Parry do not mention, however, is that this "third place" releases cancer from being a silent, private story locked within the "first" and "second" places. The voice(s) of the cancer experience are finally free to add to and shape the stories of others – redefining illness and health along the way.

Calling a Gilda's Club centre a "third place" not only acknowledges its social dimension as complementary to both the domestic setting of one's home and the institutional setting of a hospital, but also recognises the fact that it is kept "alive" by the free exchange of stories and experiences. Recalling Tuan's remark that places for the genuine exchange of feelings between people cannot be deliberately designed, being a "third place", however, enables this to naturally happen. As a "third place", it

¹⁰ Troy D. Glover and Diana C. Parry, "A Third Place in Everyday Lives of People Living with Cancer," pp. 101-2.

simultaneously becomes a place of story-telling and sharing through social interaction. Unlike a hospital, a Gilda's Club centre is shaped by what is being told about the disease, rather than by any attempt to get rid of it. With the sole intention of offering comfort and hope to people affected by this dreaded disease, the Gilda's Club centres are not designed with health-care or therapeutic treatment in mind. In fact, according to Glover and Parry's study, it is simply a place that hosts social activities, which resembles Tuan's idea of a domestic house where people pause, rest and are cared for by others:

The tastefully and elegantly decorated rooms within Gilda's Club created an effective home-like ambiance for people using the space. In particular, the functional spaces at Gilda's Club were designed to allow for all kinds of recreational use, both group-based (e.g., activities and programs) and individual-based (e.g., reading, browsing the internet), which allowed members to 'do what they wanted' and view Gilda's Club as a 'drop-in environment.' Accordingly, the spaces at Gilda's Club complemented the activities that took place within them and never took away from the Club's purpose: to support people living with cancer.¹¹

This description shows that within a healing place, social events and activities are what give such places a therapeutic quality. But we must also be reminded that the Gilda's Club Centres also begin as an empty space. This implies that spaces slowly become places as we get to know the surrounding objects and make personal connections with them, much in the same way that we familiarise ourselves with a new neighbourhood. The initial, blurry understanding of a new space becomes concretised as we learn to associate it with objects such as buildings, landmarks, street corners, and neighbours' houses. Space then begins to make sense as a real, physical entity.¹² This process can also be likened to the ways in which we find meanings in nature. There are places in nature that we associate with healing – from hot springs, meadows, and mountains to a little path in the countryside. To have a space of healing, we must first be able to identify the surrounding places/objects as

¹¹ *Ibid.*, p. 105.

¹² Tuan, *Space and Place*, pp. 17-18.

healing, or conducive to healing. As such, demedicalisation is the first step to constructing a space of healing.

Demedicalising Space

Demedicalisation is the process of ensuring that patients are not treated as objects beneath the clinical gaze. Individuals in a demedicalised space are free to “do what they want” in a “home-like ambiance” that opens the places within it to new healing experiences. In most Western societies today, there are at least two important spaces of healing that are free from the reign and control of the biomedical doctrine. One is the Internet, and the other is a physical space that appeals to our personal ideals and aesthetics of healing. While the latter is more subjective, cyberspace is very public. It is where patients go to find unlimited resources on what they need to know, particularly information about their illnesses that is not necessarily revealed by their oncologists/physicians. Advice and opinions (some professional) about alternative treatments and options are freely available. Furthermore, the Internet is a space where patients can connect, albeit only in textual form, and share the feelings and emotions that they might not be able to express at home, which makes cyberspace a community that is constantly expanding.

In her observational study of how people with Multiple Sclerosis make use of the Internet to consume, communicate, and embody medical information, Hester Parr finds that the definitions of “healthy” and “ill” bodies are constantly contested and negotiated in this virtual space. Parr notes that due to the rise in the individual consumerism of medical information, the physically ill body is becoming the focus of community cohesion in virtual space.¹³ That is, Internet users become medical knowledge experts through their own embodied experiences with diseases such as

¹³ Hester Parr, “New Body-geographies: The Embodied Spaces of Health and Medical Information on the Internet,” *Environment and Planning D: Society and Space* (Vol. 20, No. 1, 2000).

Multiple Sclerosis, which “provide a physical-biological foundation for the debates (and occasional resistances) of chat-room users as they redefine their ill bodies”. Similarly, people living with cancer also rely on the Internet for support and the exchange of information.¹⁴ Using the geography of both their bodies and emotions as the basis for a virtual community allows people living with cancer to create cohesive communities where they can talk about their distress and disentangle their physical and emotional experiences. Such communities are not confined by any physical materiality or boundaries, as Parr’s case studies show. Instead they are experienced as reality by representing/manifesting the disease and the ill body as text. It is this collective textual exchange that then gives meaning to what used to be considered an “undefined” and “unconfined” abstract notion of space. In this regard, Internet forums constitute important spaces in which people with cancer redefine their own personal space of healing and their ill bodies and illness experiences take part in carving out a space where their stories are stored.

The second type of healing space concerns the figurative rather than the literal. As I mentioned, place can be understood as the passive outcome of a spatial process, as in the aforementioned example of moving to a new area without knowing any of the street names or landmarks. Likewise, we can also familiarise ourselves with what its objects mean to us subjectively. When we consider, for instance, the space of a bedroom, the space next to a window, or even the space of a chapel, all are meaningful to us because of the symbolic objects involved: the bed (to rest and sleep on), the window (that opens to the outside world and/or allows us to daydream), and the cross and altar (that perhaps symbolises one’s faith or heritage). Interestingly, this can also be highly subjective. The particular way that the sun shines through the

¹⁴ Websites such as www.cancerforum.com.au/forum; <http://www.bcaus.org.au>; and www.friendsinneed.com among many others, are places for people to go and discuss in chat rooms or gather information from bulletin boards.

window on the floor can warm not only the space, but also the heart of some people. Or, it might take a smell in an old corner shop to remind an individual of happiness and fill her with memories, but it may not have the same effect in another person. We do not necessarily need our surrounding environment to be filled with other people and social activities. Space, in this sense, is experienced sensually and therefore it speaks to us affectively. Moreover, we need the visual fields of both our eyes to produce our sense of depth, such that when blindfolded, we instinctively reach out to explore the space through touch in relation to where we are. Other non-distancing methods enrich the geometric and spatial characters of a space, including words such as “sharp”, “flat”, “heavy”, “musky”, and “light”, which are often used to describe the texture, mass, and volume of a space through our senses of touch, smell, and taste.¹⁵ These borrowed descriptions of the sensations of a space imply that it can be explored both viscerally and subjectively and represented via visual or literary imagèries in visual art, literature, and architecture that use colour, form, shape, words, and texture.

Because residents and patients in health-care settings are susceptible to the different ambiances within the overall environment, what Marc Schweitzer and colleagues refer to as the “sensory environment” should be important in every health-care facility for they directly work on our subjective ideal and aesthetics of healing. According to Schweitzer et al., healing is a collaborative process in which patients and their family members should feel connected to the staff that runs an environment and the environment, in turn, should support such connections and interactions.¹⁶ Thus, to demedicalise a space is to create a spatial language that links us symbolically to a healing ambience and enhances a sense of collaboration in the healing process. To create an environment that makes us feel our ideals are met, demedicalisation

¹⁵ Tuan, *Space and Place*, pp. 12-3.

¹⁶ Schweitzer et al., “Healing Spaces: Elements of Environmental Design That Make an Impact on Health,” *The Journal of Alternative and Complementary Medicine*, (Vol. 10, Suppl. 1, 2004) p. S-78.

cannot be achieved simply by adding or removing something to or from a setting, or by altering the colour of the walls or changing the size of the windows. The quality of the material, the size of the space, and the function of the objects in the setting do not matter. To create an ambiance that is supportive and therapeutic, a space must make the user feel “at home”, both within her ill body, and within the space around her.

A hospital is a good example of how demedicalisation works. Our general impression of a hospital is that of a place where only the sick and the injured go for treatment. Unlike a shopping mall, train station, or hotel, the hospital is not a place of transition. Although it is open to the public, people do not go there for leisurely fun. Sharing the same Latin root with the word “hospitality”, the word “hospital” used to mean an apartment for strangers or guests. Today, it signifies an institutional space in which exclusively medical services are delivered. Although we seldom associate the prescription of painkillers and tranquillizers or the surgical removal of a brain tumour as “therapeutic”, the hospital is nonetheless a place we turn to hoping that we will leave with a clean bill of health. It is associated with “healing” because it embodies the technologies that help regenerate and repair what is wounded or malfunctioning. From the perspective of Western allopathic medicine, the repair and regeneration processes are precisely what define healing. In this sense, a hospital does not require “human touch” as long as it has the professionals, specialists, and technologies needed to make the health threats go away. Hospitals can be considered what Edward Relph refers to as “inauthentic” places because they are usually associated with standardised landscaping, non-distinct environments, and generic interior design and furnishings that offer no recognition of the importance of place.¹⁷

¹⁷ See Edward Relph, *Place and Placelessness* (London: Pion, 1976).

Today's public hospitals, however, are growing more mindful of the kinds of environments they create. Although still cold and sterile to most people, visitors are now greeted by paintings on the walls, a florist by the entrance, and maybe a café or a gift shop. In fact, the importance of a hospital's interior environment is now of interest to medical geographical and sociological studies, particularly in relation to the relationship between environment and place and its effect on healing. For example, many studies have shown that people tend to suffer less post-operative stress if they are in a hospital room where they can look out a window or have access to other forms of nature while they are recuperating. Thus, gardens, for instance, are being strategically incorporated in many hospitals' landscape designs.¹⁸ The design of the hospital as a demedicalised space has come a long way as diseases have evolved. We used to need a sterile space to effectively treat infectious diseases; today, however, chronic and degenerative illnesses call for spaces in which patients are treated as individuals rather than as machines waiting to be fixed. In this context, in addition to dispensing medicine that can be used to kill germs and viruses and using technology and equipment to examine the inside of a patient's body, healing is materialised in the relationship between the patient and the environment. Being able to look out the window brings patients into contact with nature and ample lighting makes everything look more cheerful and safe, such that patients are not constantly reminded by their environment that they are suffering from an illness – finally, they can begin to heal.

As such, the healing space is built on its relation to the natural environment and the presence of symbolic objects that are meaningful to the patients or can remind them of home. This perception echoes the words of architect Frank Lloyd Wright:

¹⁸ C. Robert Horsburgh, "Healing by Design." *New England Journal of Medicine* (Vol. 333, No. 11, 1996), pp. 735-740.

“Hospital patients should never be imbued with the idea that they are sick... health should be constantly before their eyes.”¹⁹ This can even be achieved through physical objects such as the fresh flowers that visitors bring. It also requires design that specifically enhances therapeutic quality, which is not intrinsic in the space of the hospital. With the emphasis placed on health, the demedicalising of a hospital space can actually turn the tables for the patient in relation to his illness. First, it helps deconstruct the hierarchy between health care professionals and patients that make medical places sites of resistance against the hegemony of medical practice. Such a deconstruction also gives patients (and their family members) a “domestic setting” in which an equal say about how they are treated is possible, making them collaborators in their own health regimes. Second, a demedicalised environment enhances mutual respect and trust between the healer and the patient and encourages social relationships within health-care settings. Third, and most importantly, demedicalisation enables the materialisation of other healing agents within a place that typically exist outside the medical context by creating a space in which the non-verbal and the immaterial can also be part of the definition of healing, such that healing becomes a form of communication and interaction between people and the spaces they inhabit.

Maggie’s Centre and the Architecture of Healing

Architectural theorist Bernard Tschumi remarks that to define space means “both to make space distinct” and “to state the precise nature of space”.²⁰ If healing is spatially related, then could an architectural space be built specifically for the purpose of healing? What would it look like and how would it function? An architectural space can be both functional and aesthetic, and thus can foster a better

¹⁹ Cited in Horsburgh, p. 733.

²⁰ Bernard Tschumi, *Architecture and Disjunction* (Cambridge, Massachusetts: London, 1994) p. 29.

connection between people and objects to create an ideal that is unique to each space. Using the example of Robert Adam's Home House as an example, Alain de Botton explains in *The Architecture of Happiness* how people can be moved by an "ideal" in architecture:

Imagine a man in an especially tormented period, sitting in the waiting room of a Georgian townhouse before a meeting. Uninterested in the magazines on offer, he looks up at the ceiling and recognises that at some point in the eighteenth century, someone took the trouble to design a complicated but harmonious moulding made up of interlocking garlands of flowers and painted it a mixture of white, porcelain blue and yellow. The ceiling is a repository of the qualities the man would like to have more of in himself: it manages to be both playful and serious, subtle and clear, formal and unpretentious.²¹

The suggestion is that perhaps it is only when one's life is in great despair and subject to a very troubled time that one is the most receptive to beautiful things, especially those that appeal to one's ideal:

It is not those creatures with well-organised, uncluttered minds who will be most moved by the sight of a clean and empty room in which sunlight washes over a generous expanse of concrete and wood, nor will it be the man with every confidence that his affairs are in order who will crave to live under – and perhaps even shed a tear over – the ceilings of a Robert Adam townhouse.²²

An architectural ideal, when applied to a healing space, must address the ideal of healing, at least spiritually. It should reach out to the personal lives and histories of those for whom it is intended and remind them of what they have and what they lack. It should address who they are and who they are not, but most of all it should act as a communication between the user and the artefact – a non-verbal exchange that appeals to the imagination. If we apply this to the context of healing from cancer, such an exchange might even include the symbolic connections between the lived environment, the disease, and the ill bodies. Therefore, a healing space should be able to shape and constantly reconfigure the illness experience, and vice versa.

²¹ Alain de Botton, *The Architecture of Happiness* (Australia: Penguin Books, 2006) pp. 149-150.

²² *Ibid.*

Similar to Gilda's Club, Maggie's Centre is a chain of alternative cancer support centres that operate on charity, fund-raising, and individual donations to provide social, emotional, and psychological support to people living with cancer. Functioning like an open-house, each Maggie's Centre provides a drop-in environment where no booking or referrals are necessary. In fact, both Gilda's Club and Maggie's Centre provide inclusive support services for people living with cancer and stress the core value of placing members/users at the centre of focus. However, the unique architecture of each Maggie's Centre marks the main difference between the two – Maggie's Centres create a space in which healing activities take place, but are not conducted entirely by humans. Like Gilda's Club, Maggie's Centre has its own story, which is presented on its website. This story begins with the diagnosis of Maggie Keswick Jenck's (the co-founder of Maggie's Centre) breast cancer that had recurred and spread to her bones, liver and brain. She was told she had only three months to live. Subsequently, she decided to try the advanced chemotherapy in the Western General Hospital in Edinburgh. When Maggie and her husband, Charles Jencks visited the hospital, however, "they have great trouble finding the room where they will hear about possible radical treatments." This experience made them realise the environment in which patients discuss difficult and sometimes life-threatening problems with medical staff plays an important role. It should be a place where patients can not only digest the information about treatment and prognosis, but also to be in private to recuperate and recollect their thoughts.²³

As this history shows, the concept behind these healing spaces arose from the experiences of a cancer patient and her struggle with the disease over many years. They are the outcome not only of her own struggle, but also of the figurative

²³ Source: <http://www.maggiescentres.org/maggies/maggiescentres/home/about/introduction.html> (Last accessed: 18 Sept 2010).

footprints she left in the places she walked through with those close to her, including the medical professionals involved in treating her cancer. According to her spouse, Charles Jencks, the original idea was to have one small room with a big window looking out onto green space.²⁴ When we look at its conception, the Maggie's Centres are no different than other cancer-care centres – a humble, social, non-medical response to cancer. However, as the idea “grew”, the spatialising process suggested that users would be able to explore the enclosed space and its materiality with their bodies and senses. Bear in mind that although we use our senses to explore and define the space that surrounds us, spatial experiences can also affect us in indirect ways that can change the way we relate to a concept, such that we are able to form new relations to preconceived concepts through our senses.

Given the success and popularity that accompany the launch of each Maggie's Centre, even Jencks found that he had to clarify the confusion that people have about the effects of architecture on health and the work and ethos of the activities that take place inside each Centre. In response to an article entitled, “Can Architecture Beat Cancer?” published by the British design journal, *Blueprint*, Jencks replies:

How could one believe architecture had such amazing powers? Even chemo, radio and the thirty or so other therapies that are mainstream practice (even some of today's wonder drugs) do not beat [cancer]... One understands why the feelings run high, but they obscure the heart of the question. Put aside the architecture for the moment, and ask the more focused question about Maggie's Centres: can their activities make a difference?²⁵

By “activities”, Jencks means more than the person-to-person social activities. As I subsequently show, Jencks is also referring to the elements and objects in these buildings that help shape the activities – the agents that take part in the social life of the space. The activities are actually carried out by the interior design of each

²⁴ Charles Jencks and Edwin Heathcote, *The Architecture of Hope*, (London: Frances Lincoln Ltd., 2010), p. 11.

²⁵ *Ibid.*, p. 40.

Maggie's Centre, leading our actions and bodily movement into the realm of healing upon entering.

Described as “mixed building type[s]”, “hybrid[s]”, and “alternative postmodern architecture”, Maggie's Centres are “like a house [that] is not a home, a collective hospital [that] is not an institution, a church [that] is not religious, and an art gallery [that] is not a museum”.²⁶ Theoretically, there is always ambiguity between an architectural space and its use that is not part of the intended design. This is what Tschumi calls an architectural “disjunction”, where space and use are fundamentally mutually exclusive.²⁷ Tschumi's argument is that because space and the experience of space do not necessarily have an a priori cause-and-effect relationship, the use of space can be subversive to social and political powers. To contextualise it within the space of healing, however, such disjunction is an integral part of the “therapy” for its inhabitants. Although it is initially built for the purpose of providing social and emotional support, it leaves room for its users to re-invent their own space via their bodily experiences and stories. Each Maggie's Centre is a healing space not simply because it might house a stress-relief class or provide information and knowledge, but because it is a three-dimensional storybook of cancer – a compilation of scientific and biographical stories that reveal something about the cancer. As I subsequently show, the buildings do represent the nature of cancer in its physical form, if only spatially rather than literally, and the fact that each Maggie's Centre is built to be “read” individually also creates a sense of exploration and the need to interpret both the architecture and cancer:

²⁶ *Ibid.*, p. 14.

²⁷ *Ibid.*, p. 19.

A Maggie's Centre will be many things to many people. It is there for anybody to use in the way they want to. There isn't a one size fits all recipe for how you live with cancer. Everybody needs to find their own way.²⁸

Each Centre is unique in its design and location, and each is commissioned to a different architect, some of which have included Zaha Hadid, Richard Rogers, Kisho Kurokawa, Rem Koolhaas, and Frank Gehry – all personal friends of Charles Jencks. The goal each time is to translate, architecturally, the myriad and yet indefinite causes of cancer. Hence, there is no generic type for a Maggie's Centre, which corresponds to the fact that there is no generic type of cancer ("Your cancer is unique."²⁹). As a result, different Centres say different things about the cancer story that require the visitors to physically play with and engage in the various metaphors of cancer, and it is precisely because each Centre is built by different architects with different experiences and perceptions of the disease that each Centre becomes a unique representation of the cancer experience. Not only is the demedicalised structural environment a refuge for cancer patients, but also by re-creating various architectural metaphors of cancer it becomes an interactive healing space that enables its users to spatially experience cancer in a more positive way without having to keep cancer out of sight.

In addition to serving as embodied metaphors of the disease itself, Maggie's Centres feature striking architectural forms that, unlike generic health-care institutions, send a message to the user (particularly those who have felt vulnerable since the moment of their diagnosis or those affected by a loved one's diagnosis) that these buildings were built especially for them. Their unique forms and shapes make a public statement that the illness their users are suffering from cannot be ignored by society, and it is the experiences and stories of their users that give rise to their forms

²⁸ Source: <http://www.maggiescentres.org/maggies/maggiescentres/home/about/introduction.html> (last accessed: 18 Sept 2010)

²⁹ Source: <http://www.cancerhelp.org.uk/type/breast-cancer/treatment/statistics-and-outlook-for-breast-cancer>

and shapes. More importantly, they say that cancer is not a taboo subject to be silenced and hidden from the public. Given their locations – usually next to or part of a hospital – the incongruent and prominent structures actually offer a certain amount of “pleasure” to the public simply through their existence. Common anxieties about cancer are displaced precisely because these architectures refuse to blend in with the environment or to conform to what a place for people with cancer should typically look like.

Maggie’s Centres as Artefacts of Healing

The Maggie’s Centres are visually pleasant not only because they are designed by internationally renowned architects, but according to de Botton, it is also because of the architectural “virtue of balance”. He claims that by juxtaposing order and complexity and mediating between the old and the new, the natural and the man-made, and the luxurious and the modest, architecture can achieve “a seductive harmony as well as a curious co-dependence, with each relying on the other to downplay its faults and enhance its charms”.³⁰ For the Maggie’s Centres, it is a harmony achieved through the balance of aesthetics and function; private and public. The function of the Maggie’s Centre as an artefact of healing is to facilitate interactions between people and objects to create a new spatial experience while simultaneously acting as a text that can be read and corresponded to through the many different ways in which people navigate their bodies and bodily movements. Each Centre is a journey through which the artefact and human are able to correspond. Unlike place-activities-based cancer-care centres, each Maggie’s Centre creates interplay between interior and external space, mediated by the presence of cancer, which becomes part of the design and spatial layout of the space. In addition,

³⁰ de Botton, *The Architecture of Happiness*, p. 195.

each Centre interacts with the surrounding urban landscape in such a way that – simply by existing next to the professional seriousness of a hospital – illness, hope, anxiety, and the necessary humour to heal are simultaneously balanced and mediated. As such, it is not only the architectural space itself, but also each Centre as an (architectural) artefact that bears the quality of healing. Indeed, most of the Centres can be studied in connection with their surrounding environments, in which the natural landscape is merged with the built space, which extends the social space into the natural space. As such, each Centre is not only a space, but also an artefact that offers a new sense of spatiality that can be used for healing.

According to Jaime Saris, the embodied experience of space and its power relations are partially the result of discourse and its operations of power and knowledge.³¹ The experience of a healing space, in contrast, opens up a new landscape that can be changeable and fluid on the one hand while conflating public/private and nature/culture on the other. In other words, each Maggie's Centre is characterised by both a sense of fluidity, and a sense of expandability. This is made possible at two levels: its interaction with its external surrounding environment and the continuous re-shaping of the space via story-telling. As I mentioned earlier, space is experienced through our senses in relation to different objects, including our distance or proximity to these objects and how they are related to our experience and felt value. By reaching out to make use of the adjacent landscape (to expand our experience of a Centre's space to include its exteriority), a new form of interaction emerges and becomes a healing space. Although human activities and social connections are equally encouraged, what makes each Maggie's Centre stand out from its place-based cancer-care centre counterparts, such as the Gilda's Club centres,

³¹ A Jaime Saris, "Telling Stories: Life Histories, Illness Narratives, and Institutional Landscape," *Culture, Medicine and Psychiatry* (Vol. 19, No. 1, 1995) pp. 41-2.

is that there is an exteriority that actively interacts with its surrounding landscape in order to give meanings to its materiality and shape. Circumscribed by its floors, ceilings, and walls, each Maggie's Centre stands as an artefact that is constantly interacting with its surrounding environment as the boundaries between in- and outside, natural and man-made, illness and healing, and presence and absence shift and settle. The Maggie's Centre in Inverness is one example (Figure 1).



(Figure 1: Maggie's Centre, Inverness, Scotland. Designed by Page and Park Architects)

According to Page and Park (the architectural unit that constructed this particular Centre), Jencks was the one who suggested that the building should mimic a dividing cell to create a parity and synergy between landscape and building:

The concepts are expressed in ambigrams inscribed into the seats [on the inverted mounds], the words "spirals" and "time" which can be read either way up to read the same way. These seats also allow a step back, that important moment in the personal history of cancer diagnosis and treatment in which it is necessary to have room and time to be able to look at the bigger picture. The seats are intended to allow you to do exactly this.³²

³² Jencks and Heathcote, *The Architecture of Hope*, pp. 109-110.

Although it encourages a pause in movement, this pause does not happen in a domestic setting, nor is it passive. Combined with the surrounding landscape, it is more like a place designed for mediation that extends the inside into the outside or, one might say it is an effect that conflates the inside with the outside. The conflation of the public/private, inside/outside, and medical/personal is also achieved through the constant symbolic presence of cancer. In addition to resembling the split cells that remind people of cancerous cells, there are also two turf mounds connected at their centres by white flashes that function as “understated metaphors of the real signals that keep cells in balance and healthy”. Although cancer is the core idea that inspires the design, it also uses the appeal of balance between contrasting elements in buildings that de Botton suggested, and in this particular Centre, the presence of cancer in scientific form is juxtaposed by an artistically rendered, bright, round shape. This allows patients to process the various objects that make up the space from a new perspective. As a result, the building transforms the patients’ feelings and behaviour using a welcoming, light-filled space designed to displace depression and fear, if only momentarily. Most notably, as a shared space, the two mounds also remind people that cancer is a shared journey – one undertaken with others who are in the same boat. Imagined from a building plan intended to illustrate a specific moment in cell mitosis when the cell splits and proliferation begins, this Centre is also an attempt to represent the communication and balance between cells. This is manifested in- and outside the building by allowing space “to flow from the mounds outside to the spiralling forms within, the shared formal language breaking down the sense of barriers between landscape and architecture”.³³

³³ *Ibid.*, p. 110.



(Figure 2: Maggie's Centre, Kirkcaldy, Fife, UK)

On the other hand, architecture can stand in stark contrast to the surrounding environment to create a healing effect. As Zaha Hadid, the architect for the Maggie's Centre at Fife (Figure 2), explains, "at the edge of the ground, there's a hollow, a kind of pit which acts as a buffer between the landscape and the parking. The building is all about the ground condition, about a structure peeling slowly away from the edge of the slope and cantilevering over the edge. It just sits there, rather precariously on the edge of the hollow". Regarding the Fife Centre's interior, rather than intentionally creating a warm/soothing lighting effect it builds on the strong contrasts between dark surfaces (metaphors for war and pain) and light-filled whiteness (metaphors for hope and life), that offers direct contact with sunlight and nature:

The interiors are bright and white, the expansive windows complemented by triangular slashes in the roof and walls; neither quite windows, skylights or framing devices they allow the envelope a seamless transition from vertical, to canted to horizontal, the envelope appearing as a continuous surface.³⁴

Therefore, it is the building's relationship with the natural setting that creates this contrast, which gives patients an immediate experience even as they enter the building. The building also does not cast cancer from the space in exchange for a healing ambience; rather, healing is made manifest through the architectural language. For instance, the long ramp acts as a friendly guide that helps smooth the transition

³⁴ *Ibid.*, p. 127.

between the angular exterior and the juxtaposed interior – literally pushing the adjacent Victoria Hospital away:

A long ramp sweeps visitors theatrically into the building. The structure takes you into its embrace – to enter it is a very deliberate decision, there are no fuzzy boundaries here... The building responds to a certain need after visiting the hospital. The process of chemotherapy and radiotherapy, it provides a place between all that and going home. It's also a kind of buffer in that sense, the idea that you re-enter the world through a small, domestic scaled environment.³⁵

The Topology of Architectural Space

To understand the topology of the Maggie's Centre, I refer to John Law and Annemarie Mol's study of the spatial characteristics of science and technology. Law and Mol argue that there are two types of performing space. One is the Euclidean space, in which place is defined by a set of relative, three-dimensional coordinates. The other is the network space, in which as long as the object and its working relations between humans and objects are stable and can be sustained, then the artefact is not necessarily mobile.³⁶ Maggie's Centres as healing artefacts would be considered stable and immobile because they move in neither of these spaces. Yet they are malleable and adaptable in the sense that their shapes evolve and change to allow new ways of experiencing while still maintaining a same-shape constancy. Law and Mol's case study examines the Zimbabwe bush pumps that spread among many of the country's villages. For the bush pumps to work effectively, they must be different in different regions; adapting themselves to different needs. Similarly, the senses are susceptible to changes during the different stages of the cancer experience including new diagnoses, post-operation, and remission; each of which generates a

³⁵ *Ibid.*, p. 127-133.

³⁶ According to the Actor-network Theory, even though the ships travelled from Lisbon to Calicut in India and back again, they kept their shape. They were immutable mobiles because a network was elaborated and performed, and the network sustained itself in a stable manner and did not budge (see John Law and Annemarie Mol, "Situating Technoscience: An Inquiry into Spatialities," *Environment and Planning D: Society and Space* (Vol. 19, No. 1, 2001) p. 611.

new set of “co-ordinates” that changes the form and shape of the experience, even when cancer is no longer “active” in the body. Given this understanding, these Centres are not about the Euclidean space (the regional, geographical location) or the network space (the relationality between objects and humans), but rather a connectedness between both the objective social space on one side of the boundary and the subjective inner space of the experiencing body on the other. Such topology enables the Maggie’s Centre to participate in the social by being both a place to tell stories and a storyteller.

Bruno Latour opines that construction is actually a form of “building”, and a building is not about the “solidity of the resulting *construct* that is in question, but rather the many heterogeneous ingredients, the long process, the many trades, the subtle coordination necessary to achieve such a result”.³⁷ Likewise, the heterogeneous ingredients of the Maggie’s Centre as both an architecture and a healing artefact need not be simply technological and autonomous. Architecture is constructed in a sociotechnical network, it is thus considered part of the social. Kjetil Fallen further explains: “Architecture is socially formed, but architecture also informs social behaviour, whilst in turn being continuously transformed by social activities.”³⁸ As we can see, each Centre encourages communication with every object and (im)materiality, including structural elements such as pillars, the shape of the door, and the colour of the walls to simultaneously create a space that “talks” to the visitor. This form of communication is different from Bruno Latour’s example of the hotel key ring that serves as an actant to replace the technology/social divide. While Latour argues that the metal key ring is actually an actant that reminds hotel guests to return their keys to the reception desk, the communication achieved by the

³⁷ Bruno Latour, “Promises of Constructivism,” *Chasing Technoscience – Matrix for Materiality*, Don Ihde and Evan Selinger (eds.) (Bloomington: Indiana University Press, 2003), p. 28.

³⁸ *Ibid.*, p. 85.

Fife Centre does not share the type of one-way nature initiated by the key ring, but rather creates something dynamic from the movements that are guided by the space through different elements such as the ramp, the door, and the corridor.

Users/visitors entering the space must first make sense of what the space tells them (there is no standard way of reading an artefact) based on their illness experiences and personal backgrounds. In this way, no two communications are the same; unlike the hotel key ring, which simply says: "Please return me to the reception desk".

From design to material form, each Maggie's Centre is an alliance between many people who may or may have connections to the experience of cancer. Each Centre also needs users/visitors and their cancer experiences to complete its existence.

Jencks offers the following description of what a Centre interior is meant to be:

Informal, like a home, a Maggie's Centre is meant to be welcoming, domestic, warm, skittish, personal, small-scaled and centred around the kitchen or place to make coffee and tea... Then there are private spaces where economic and psychological questions are discussed... Finally, there are the gratuitous spaces: the garden, the architectural gestures, or sculptures, or collections of knick-knacks that exist for themselves.³⁹

He notes that it is a productive space that defines the Centre:

For one thing it creates a sense that everyone is in it together, patients and fundraisers, carers and those who drop in for tea, staff and doctors. This informal continuity, the mixture, overcomes the sense of isolation that usually divides a business into the centre and periphery. Beyond such immediate benefits the blend of functions has also made them of more interest to architects and students, especially in a period when many building types have been reduced in scope to a single use.⁴⁰

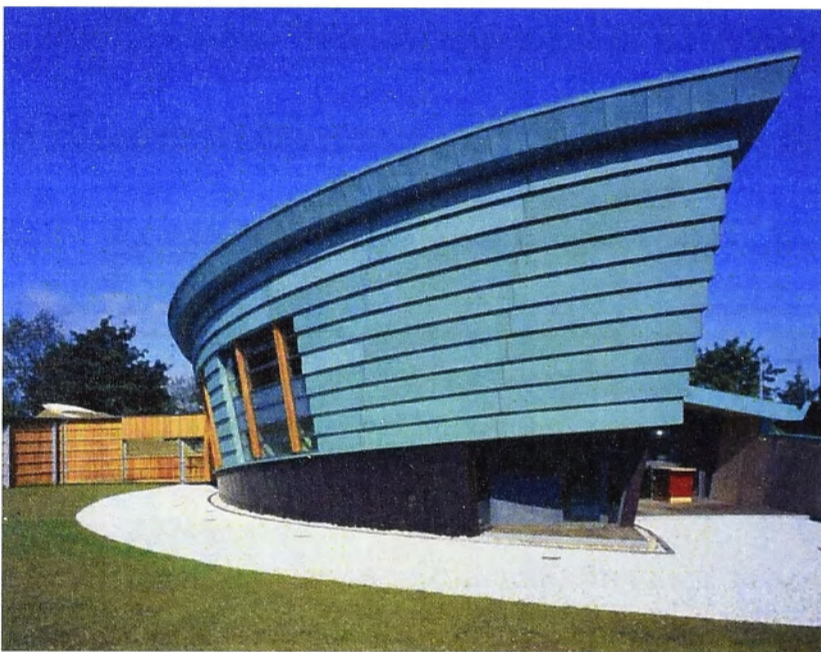
If the Centre is a space built on the story of cancer, then every interaction between the space and its users makes it both a place to tell stories, through its construction and design, and a story-teller, through its social participation.

³⁹ Jencks and Heathcote, *The Architecture of Hope*, p. 13.

⁴⁰ *Ibid.*, p. 14.



(Figure 3: Exterior of Maggie's Centre, Inverness, Scotland)



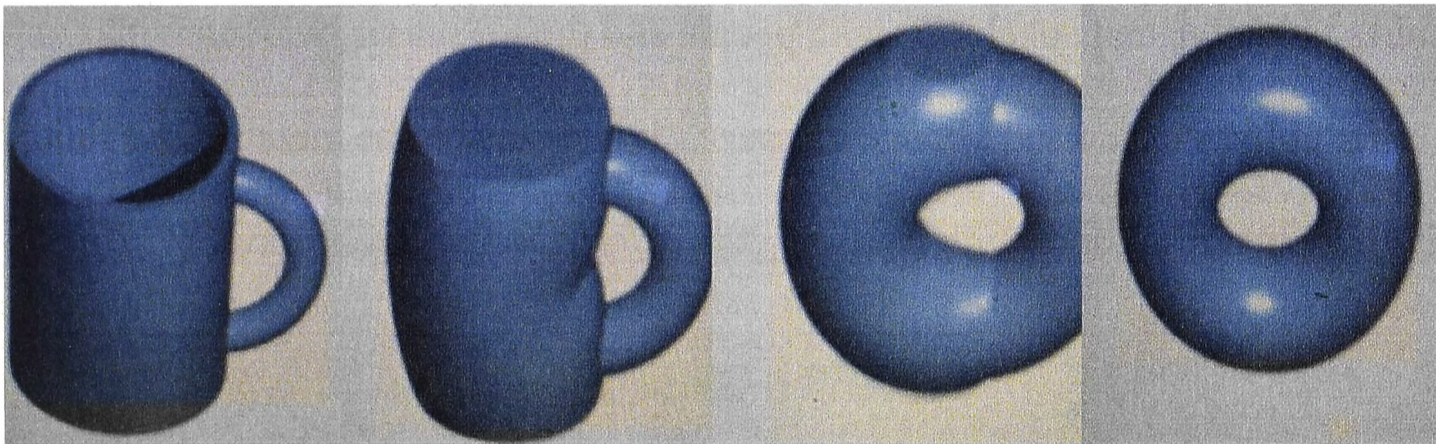
(Figure 4: Another view of the exterior of the Inverness Centre)



(Figure 5: Interior of Maggie's Centre, Inverness, Scotland)

The Maggie's Centre in Inverness (Figures 3-5) is often mistakenly believed to have been designed like a boat "where none of the walls are straight [and] all the

doors are curved” when in fact, it was designed as an upside-down mound. It makes everyone, including Jencks and the other architects, wonder what is causing this alteration of perspective and optical illusion.⁴¹ Our ability to look at things differently in relation to our experiences via a building’s design and metaphorical use of space also requires that we feel differently to make different linguistic-cognitive connections. These healing spaces do not necessarily heal in a biomedical sense, but they change the “form and shape” of cancer, which results in a form’s ability to change shape within its own space in the same way that a mug can be changed into a donut [Figure 6].



(Figure 6)⁴²

Built and designed to empower the patient, the rich metaphorical use of space and its relation to objects, images, and symbols assures that those who use these Centres – amid the options, choices, and information that overload the medical system – benefit from the openness of the possibilities they provide. By emphasising their role as neither treatment centres nor hospices and with the notion that self-help is essential, the Maggie’s Centre buildings stand not only as “third places” where social interactions are possible, but also as ornaments and symbols of hope to be interpreted and read by their users according to the users’ personal beliefs and aesthetics. The desires and needs of people living with cancer drive how each Centre turns out, but

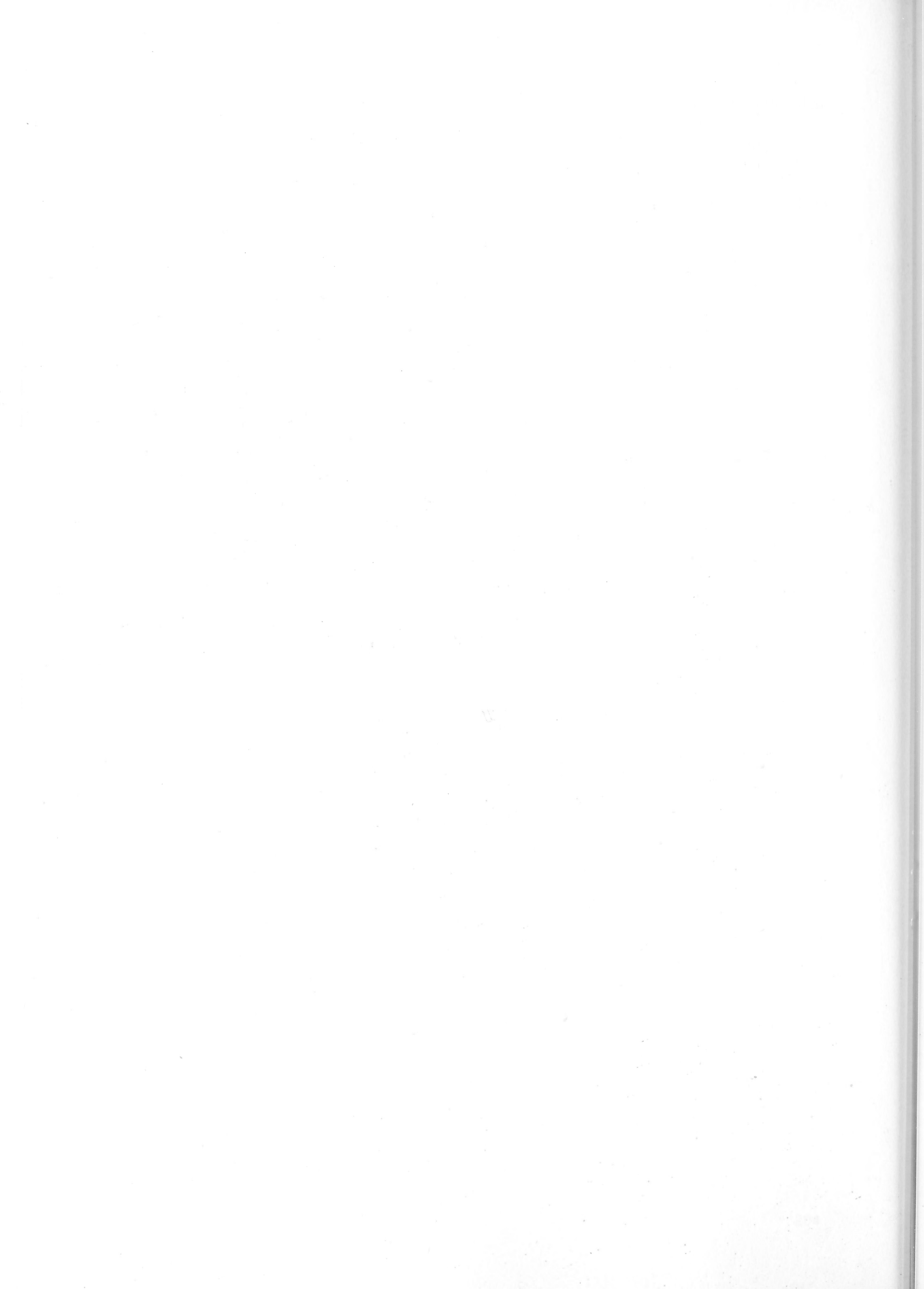
⁴¹ *Ibid.*, p. 42.

⁴² Image taken from:

[http://en.wikipedia.org/wiki/Wikipedia:Today%27s_featured_picture_\(animation\)/July_18,_2007](http://en.wikipedia.org/wiki/Wikipedia:Today%27s_featured_picture_(animation)/July_18,_2007)

more importantly, each Centre is built as *what cancer is*, or what it can be (rather than what it is *not*), which enables each Centre to embody a different cancer reality.

By first analysing the function of organisations such as Gilda's Club and, later, Maggie's Centre, I show how social and communal support centres for people affected by cancer can be more than just edifices that aim to eliminate the disease. Not only are these places where people exchange their stories, they also actively participate in their own story-telling by guiding users/visitors' spatial experiences. Hence, healing spaces are not passive, static, or fixed. Created from stories of illness experiences, the healing space as a healing artefact is not a finished product. It continues to evolve and cohabit with people and their diseases, with activities, and with other objects inside and outside its space. It is created to be mutable and fluid that ultimately corresponds with its users during their journey of healing.



Chapter Six – Imaginations that Hope

Cancer is now generally believed to be a “treatable” disease, but one that cannot be completely cured. With all of the newly invented experimental drugs and ever improving treatment technology, which boasts minimal side effects, many cancers today are marked by a prolonged remission stage from which spring tales of miracle cures and heroic survivals that encourage others. The cancer trajectory in most cases now consists of a longer period of *living* than of *dying* of cancer. However, we should bear in mind that living with cancer does not mean finally claiming victory over the disease. At best, it means surviving the initial diagnosis can temporarily interfere with the “schedule of death” brought on by the disease. Despite this borrowed time, cancer still lives in our lives like a nightmare – constantly reminding us of what it could eventually do. *Living with* cancer also implies that as long as we are still living, there is no guarantee that cancer will never return – or occur. We should not be misled into thinking that once a tumour has been surgically removed and remission has been achieved, that the cancer experience is over. On the contrary, the healing journey actually comprises more of the cancer experience than the processes of diagnosis and treatment. Therefore, the cancer experience, whether it is our own or that of another, exceeds the body and its suffering to include the deeply personal and private – such as one’s secret prayers and the psychological crutches one depends on for survival. The cancer experience is lived and sustained through hope and imagination.

As long as we are living, whether with or without cancer, we hope. We hope that cancer will not happen to us and our loved ones. We hope that there will not be a metastasis or a recurrence. We hope that we, or whoever else is fighting cancer, will survive. Given the fact that hope is what sustains us throughout the cancer

experience, what happens if hope exhausts itself prematurely? Are we thrust into an even more vulnerable position when hope fails, and if so, is it better not to hope in the first place? More fundamentally, where do we find hope and what does hope consist of? In this chapter, I attempt to answer these questions by addressing the journey of healing and how the notion of hope can deliver us from the space of cancer onto the journey of healing. I draw on nursing and palliative care literature on how family members deal with their loved ones dying (of cancer or other serious, chronic illnesses), and examine how hope serves to sustain one's illness experience and for family members to survive the cancer of their loved ones. In fact, this particular body of literature is useful in showing what dying patients and their loved ones are facing and the strategies they are using to alleviate the pain of losing their loved ones. Drawing on their case studies, we can catch a glimpse of what people actually do in order to sustain hope. Specifically, I show that hope is visual and that the ability to visualise something different and better than the current situation is a coping strategy. When the illness seems too painful to bear, imagination becomes a crucial tool for the emergence of hope.

This chapter is divided into two parts. First, I outline the theory and theorisation of hope that identify it as an affect characterised by excess. By recognising hope as a drive or energy that exceeds our rational impulse to understand or give it a fixed meaning, I explore the workings of hope, including how it takes place and how it is enacted by the individual as understood and theorised by philosophers such as Brian Massumi, Alphonso Lingis, and Ernst Bloch and cultural geographer, Ben Anderson. I show that hope is visceral and ambiguous; a discontinuity from the past, so that it can keep us moving in the "here" and the "now". More importantly, it is intuitive, repetitive, and coterminous with desperation. Because this chapter is not a philosophical examination of how hope takes place in

the healthcare setting, I limit my inquiry to the function of hope as an affective energy for the purpose of investigating how it is being used and transmitted affectively. The benefit of my inquiry lies in seeing how hope is used to survive other people's cancer, specifically that of a family member. In this way, hope is not only driving the individual to reinvent the self or transform a reality, but to a cancer patient's desperate family members, hope becomes a matter of constant adjustment, negotiation, and imagination. In addition, because hope is visual, I use this chapter to analyse a set of "useful" and "useless" images that are used to describe cancer. Roughly speaking, useful images include the use of metaphors and images that give us hope in the face of cancer by cultivating a better understanding of the disease or visually inspiring us to create a positive impact. In contrast, useless images are imaginaries that are deemed "irrelevant" to the current cancer discourse. It is precisely because they are "useless", they are seldom discussed within our popular culture or academically. However, they are the blueprints for hope. I also argue that hope – whether generated by useful or useless images – is also what allows "magic" to happen in our daily lives.

Magic appears as a wonder in the eyes of the spectator, but it is not entirely a fantasy or a dream. Hope, in this regard, is like magic because all it takes is the well-timed, skilful trick of misdirection to create an optical illusion in the ready-to-believe eyes of the spectator. Such misdirection allows us to see something unlikely happen that appears to defy natural law (e.g., making a person disappear from a box). Ultimately, like all acts of self-transformation in desperate situations, it is up to us to re-invent our realities for ourselves via the use of imagination. I introduce two examples: *The Clink of Ice*, a 2010 film directed by Bertrand Blier and Jonathan Carroll's 2008 novel, *The Ghost in Love* to illustrate what "useless" images are and how, like magic, they help produce new possibilities that exceed the limits of reality,

the laws of nature, facts, and theories. Meanwhile, the question remains: can we assume that a new, collective kind of hope is possible if so, would such a hope also serve as the product of an imbrication with both private and public imagination, layered with reality to allow us to see the present as being full of possibilities?

The Function of Hope/Despair

To be human is to hope, and even though hope is a primary human emotional attitude, it remains complex to understand and describe. How does a person who is seriously ill with a life-threatening disease find hope, and what does it consist of? We seldom consider the fact that hope has always been treated as a unanimously positive thing when in reality it has a “bad reputation” that we consciously overlook. In *Images of Hope*, William F. Lynch articulates this un-noticed aspect of hope in the following way:

It comes down to this, that for many people hope really means despair. As we use language, when we say that a man has hope, we mean that he is in serious trouble. When we say that someone has hope, we usually imply that he has nothing else, and that he is close to despair.¹

As a Christian theologian writing about the mentally ill, Lynch asserts that it is up to us to use our God-given creativity and imagination to help those who cannot imagine and are therefore paralysed by hopelessness. More importantly, Lynch claims that as long as our imaginations and wishes are grounded in reality and are not sinful, they are God’s way of communicating autonomy to us. According to Lynch, the ability to imagine and hope is God’s gift to humans in times of desperation. His argument also leads us to conclude that the function of hope is that of a natural defence mechanism (God’s given gift) against what we cannot handle.

¹ William F. Lynch, *Images of Hope: Imagination as Healer of the Hopeless* (Baltimore, Maryland: Helicon Press, 1965), p. 22.

However, although hope, in Lynch's opinion, is necessarily associated with faith, particularly religious faith, one does not have to be Christian or religious to experience hope. Cancer invokes a fear of death in most people's psyches. This fear of death is not only the fear of nonexistence, but also encompasses "loneliness, the unknown, pain, loss of control, and emptiness". Citing Ernest Becker's *The Denial of Death*, Melbourne palliative care physician Simon Wein writes in *CancerNetwork*² that while we are able to repress our awareness of death most of the time, a cancer diagnosis prompts this fear to resurface and the human psyche responds with a variety of defence and coping mechanisms to re-suppress and psychologically avoid the fatality of death.³ Thus, hope means more than just passively waiting for something to change or for the next biomedical miracle to come to our rescue. Philosopher Mary Zournazi states that hope "is not simply the desire for things to come, or the betterment of life. It is the drive or energy that embeds us in the world".⁴ Hope is not intrinsic within a situation, nor is it a personal quality, but rather it grounds us in the present regardless of past experiences. As such, it follows that no individual is more predisposed to feeling hopeful than the other, and no situation or circumstance is naturally laden with more hope than what comes next.

Hope is the excess/affect that cannot be rationalised or serve as a stable signifier because it overflows the "script" in all descriptions. Hope is as elusive as a half-remembered song or the scents in the air on an autumn evening engendering a mixture of visceral and ambiguous feelings and moods. These feelings and moods are not natural parts of the music or the air; rather, they are embedded in a person's life and experiences. Hope is also unpredictable and contradictory at times. As Ben

² CancerNetwork.com is the official website of the Oncology Group, whose publication *Oncologies* is an international journal for cancer research and treatment.

³ Simon Wein, "Cancer, Unproven Therapies, and Magic," *Oncology* (Vol. 14, No. 9, 2000), p. 1345.

⁴ Mary Zournazi, *Hope: New Philosophies for Change* (Routledge: 2002) p. 15.

Anderson argues in “Becoming and Being Hopeful”, hope does not simply emerge from humans or non-humans “in” Euclidean space or “in” linear time.⁵ Instead, feelings like hope arise when a situation is least likely and they defy any logical causal relations. Brian Massumi defines hope as the realisation of a margin of manoeuvrability – an opening for experimentation, such that hope becomes a chance to potentialise a situation from which power comes up *with* us, and this power:

‘informs’ us, it’s intrinsic to our formation, it’s part of our emergence as individuals, and it emerges with us – we actualise it, as it in-forms us. So in a way it’s as potentialising as what we call freedom.⁶

With this in mind, we can examine the significance of the “emergence” of hope and how it can ultimately free us. When we can no longer take the future for granted or expect things to “naturally” happen in our favour according to the logic of time or the course of events, this feeling of helplessness and despair is enacted by the individual to establish new relations and a new space-time experience. Anderson explains the paradoxical enactment of hope and despair:

Hope, therefore, has a contradictory place in relation to everyday life. This disillusionment that provides a kind of affective imperative to welcome, and be open to, a good future is itself called forth from how a space-time of experience emerges from the movement and qualification of affect. The absence, or desperation, that is part of hope is not merely a possession of the individual but is a question of how the emergence, movement, expression, and qualification of despair enact an individual... Becoming hopeful is marked, therefore, not by a simple act of transcendence in favour of good elsewhere or elsewhen but by an act of establishing new relations that disclose a point of contingency within a present space-time.⁷

Hope and change work only in the present to renew one’s feelings and enable all kinds of possibilities for the “here and now”. As philosopher Alphonso Lingis notes, hope only “arises in a break with the past. There is a kind of cut and the past is let go

⁵ Ben Anderson, “Becoming and Being Hopeful: Towards a Theory of Affect,” *Environment and Planning D: Society and Space* (Vol. 24, No. 5, 2006), p. 735.

⁶ Brian Massumi, “Navigating Movements,” *Hope: New Philosophies for Change*, ed. Mary Zournazi (Routledge: 2002) p. 223.

⁷ Anderson, “Becoming and Being Hopeful,” p. 744.

of".⁸ What Lingis means is that hope is, strictly speaking, something that enables us to re-situate ourselves at a discontinuity in time. By letting go of the past, we find ourselves on a new path leading to the perpetual unfinishedness of the present.

Finally, hope is intuitive and repetitive. Most people experience hope in various forms throughout different stages in their lives. Some hopes materialise into reality while others remain unfulfilled desires. Nevertheless, we can always count on the fact that it is only against evidence that hope arises or, as Lingis explains, to hope is always to hope against hope. Hope is what unknowingly keeps us in action when we are stuck at the threshold. For example, if we expect the computer to turn on when we push the power button, naturally there is no need to hope that it will happen. In contrast, if for some reason the computer does not turn on when we press the power button, despite the fact that it is plugged in, we will try the power button again (and again, and again) *in the hope* that the computer will turn on. Likewise, a cancer patient can be understood as being caught at the threshold of light and darkness, or between life and death – driven by hope's action. According to Ernst Bloch, this is not a disempowering situation:

Hope has projected itself precisely at the place of death, as one towards light and life, as one which does not allow failure the last word; thus it definitely has the intentional content, there is still *recue* – in the horizon.

Thus,

Danger and faith are the truth of hope, in such a way that both are gathered in it.⁹

We can probably go even further based on the above observations and say that hope is the capability of and capacity for a sense of aliveness (an urge to find something to do, such as continuing to push the power button). It is also the

⁸ Alphonso Lingis, "Murmurs of Life," *Hope: New Philosophies for Change*, ed. Mary Zournazi (Routledge: 2002), p. 22.

⁹ Ernst Bloch, *The Principle of Hope*, Trans. Neville Plaice, Stephen Plaice and Paul Knight (Oxford: Basil Blackwell Ltd, 1986) p. 112.

realisation of one's power to act because we see the potential in each situation, particularly when we are forced against a margin or threshold and confronted by a previously unknown manoeuvre.¹⁰ Hence, in the case of illness it would be too simplistic to equate hope with the mere wish to survive or the will and courage to beat cancer because hope, in itself, is "not-yet-conscious" – defined by Bloch as a "class of consciousness that is itself to be designated not as filled but as anticipatory".¹¹ This means that this feeling of hope (and hopefulness) precedes action. Thus, the action of pushing the power button on the computer is not the result of hope, but an enactment of hope. This distinction can also be understood in the way we blush when shamed or the way we feel heat in the body when angry. Hope moves through the body as a not-yet-conscious force and, as if possessed by it, we rise out of the sick bed or stubbornly continue to push that power button. Having briefly outlined some theorisations of hope and the necessary conditions for hope to take place, I turn my focus to understanding how hope is used as a coping mechanism to survive other people's cancer.

Cancer as Family Crisis

Cancer is a family disease with a dense, gravitational tug that pulls everyone and everything into its orbit. Psychologist, Elaine Hatfield, and social neuroscientist, John Cacioppo, argue that there is a tendency for people to mimic and synchronise with the facial expressions, postures, and verbalisation of others. When talking to a depressed person, we may feel depressed ourselves, whereas talking to someone who feels buoyant may make us more likely to feel good about ourselves. This phenomenon is known as "emotional contagion" and it is "best conceptualised as a multiply determined family of social, psychophysical and behavioural phenomena".

¹⁰ Massumi, "Navigating Movements," pp. 211-212.

¹¹ Bloch, *The Principle of Hope*, p. 113.

Theoretically, emotions can be "caught" in many ways. According to Hatfield and Cacioppo, this phenomenon is particularly common among couples who are passionately in love, mothers and their infants, and people with a psychological investment in each other's welfare, such as teachers and their students or therapists and their clients.¹² However, despite the significant role that family members play in a patient's emotional experience of an illness, most studies of the cancer experience have continued to focus on the patient. Given the fact that, in reality, family members cannot do much more than gather information about the illness and brace themselves against what lies ahead by trying to keep reality in check, how they, as observers, sustain their hope should be considered more than just a manifestation of their love for the patient. For example, studies have shown that spouses actually worry more about their spouse's (the patient's) future than the patient does and patients' family members and loved ones worry equally about their own personal health and that of the patients. Nonetheless, they receive less social support than the patients.¹³

Stories about what these family members and loved ones go through as observers are also often overlooked. The existing cultural and sociological research on the topic of cancer, particularly matters of death and dying, is predominantly patient-oriented despite the fact that family members (and/or caregivers) are just as susceptible to subsequent problems such as depression or grief when the loss of a loved one is anticipated. Few psychological and behavioural interventions have been developed to enhance the quality of life for this group. True, there are support services and bereavement counselling for family members coping with their loss and

¹² Elaine Hatfield, John T. Cacioppo, and Richard L. Rapson, *Emotional Contagion* (Cambridge University Press, 1994), pp. 165-6.

¹³ For example, see SH Davis-Ali, MA Chesler, and BK Chesney's "Recognising Cancer as a Family Disease: worries and Support Reported by Patients and Spouses," *Social work in Health Care* (Vol. 19, No. 2, 1993) pp. 45-65.

grief after the death of loved ones, but research and support services that target the various aspects of families' physical, psychological, spiritual, and behavioural adjustments to cancer remain sparse.¹⁴

When someone is diagnosed with cancer, not only must the patient fight for her life, but also the patient's whole family must find a way to survive the disease. It has long been recognised by medical sociologists and anthropologists that illness afflicts both individual bodies and lives and the family as a system. It changes relationships and reconfigures them in profound and often permanent ways. Cancer changes families in the long run, as *cancer.net*, an online information resource from the American Society for Clinical Oncology, confirms:

Cancer doesn't affect just one person. Cancer affects couples, families, and friends. The complex feelings and lifestyle changes that follow a cancer diagnosis can be almost as overwhelming for family members and friends as they are for the person with cancer. Cancer changes the way you relate to your family and friends, and the way they relate to you.¹⁵

For the family, it is an emotional survival and while family members often play the double role of keeping the family together and caring for the patient, their emotional needs have been largely neglected by healthcare professionals and institutions. Family members must survive as a unit by trying to make life as liveable as possible for each other. Not surprisingly, during this period, family members are especially sensitised to what everyone around them does/says/thinks/feels and small changes in the patient's condition can affect not only family members' moods and family dynamics, but also the ways in which they perceive the reality of the illness and their adjustment of hope.

¹⁴ Youngmee Kim and Barbara A. Given, "Quality of Life of Family Caregivers of Cancer Survivors: Across the Trajectory of the Illness," *Cancer (Supplement: Cancer Survivorship: Embracing the Future, Vol. 12, Issue Supplement 11, 2008)*, pp. 2556 – 2568.

¹⁵ Source: <http://www.cancer.net/patient/Coping/Relationships+and+Cancer/Family+Life> (Last accessed 5 November 2011).

In addition to adopting a false cheerful mood for the sake of sick loved ones, it is also common to find family members who continue to visit and communicate with a loved one who is suffering from a brain injury or is in a coma at the hospital. The belief that the injured can hear them is intransigent because it is what they need to sustain hope. Indeed, in the study conducted by Sofie T.L. Verhaeghe et al. regarding how the family members of coma patients find hope, the authors note:

Hope is not only indicative of the emotional state of family members; it also determines the possibility of keeping going, continuing to function, and making sure that the necessary activities are undertaken to maintain the best care and the best prospects for the patient and to make life liveable as possible for the other family members.¹⁶

To understand how hope produces meaning in the face of death for observing family members, or the momentum to keep going despite the lack of professional support, we must look at the function of the nuclear family. The nuclear family has always been understood as a “unit” in most Western societies and is defined as more than just the sum total of its individuals. Pioneering American family sociologist, Ernest W. Burgess, claims that the model structure of families shifted from “extended” to “nuclear” following the Industrial Revolution and that its “primary functions had changed from social-institutional to emotional-supportive”.¹⁷ It therefore comes as no surprise that when someone is diagnosed with cancer, most family members describe the treatment and the repeated, long hospital stays as “traumatic”. As Maria Björk et al. observe:

¹⁶ Sofie T. L. Verhaeghe et al., “The Process and the Meaning of Hope for Family Members of Traumatic Coma Patients in Intensive Care,” *Qualitative Health Research* (Vol. 17, No. 6, July 2007) p. 733.

¹⁷ Ernest W. Burgess, *The Function of Socialisation in Social Evolution*, cited in Vern L. Bengtson, “Beyond the Nuclear Family: The Increasing Importance of Multigenerational Bonds,” *Journal of Marriage and Family* (Vol. 63, No. 1, 2001), p. 1.

Family members experienced that their family's lifeworld fell apart, or broke. All that was safe, secure, and well known disappeared and was replaced by fear, uncertainty, chaos, and loneliness.¹⁸

According to their empirical study, when a loved one, particularly a child, is diagnosed with cancer, "families intuitively started striving to survive almost immediately after they found their life world had fallen apart".¹⁹ By "life world", the authors are specifically referring to the "pregiven" or the world as immediately experienced in the subjectivity of everyday life. We all live in a life world with other overlapping life worlds. When this subjective world is broken, what was earlier experienced as normal immediately disappeared.²⁰ Bjork et al.'s subjects' intuition to survive is close to the survival instinct and allows family members to see the potential in situations, such that a power arises from the field of potential and drives them to stay calm and take control.

The family members of cancer patients must simultaneously struggle with several aspects of the disease, which means that for them, cancer is not a singular event exclusive of the outside, social world. The lived relations between cancer patients and their families are always changing and readjusting. Depending on the seriousness of the illness, family members often end up expanding their everyday relations to include nurses, doctors, and other healthcare staff that are there to support the ill loved one. Sandra Eggenberger and Tommie Nelms' study on the experiences of families with members hospitalised in an Intensive Care Unit (ICU) note that family members often feel that they are *suffering with* the loved one. This indicates that families feel connected to the ill person through their suffering, albeit the suffering that the family members experience is not physical. According to the

¹⁸ Maria Björk, Thomas Wiebe, and Inger Hallström, "Striving to Survive: Families' Lived Experiences When a Child is Diagnosed with Cancer," *Journal of Paediatric Oncology Nursing* (Vol. 22, No. 5, 2005), pp. 265, 268-9.

¹⁹ *Ibid.*, p. 273.

²⁰ *Ibid.*

subjects in Eggenberger and Nelms' study, there is often a preoccupation with the need to protect and to shield one another from the deep emotions and any harm generated by the illness experience and what emerges is a "powerful bond [among one another] as they suffered the experience of critical illness alongside other family members".²¹ This sense of *suffering with* is not limited to the person who is ill, it also happens *with* those who are observing. This dynamic helps paint a clearer picture of the lived psychological spaces of these families:

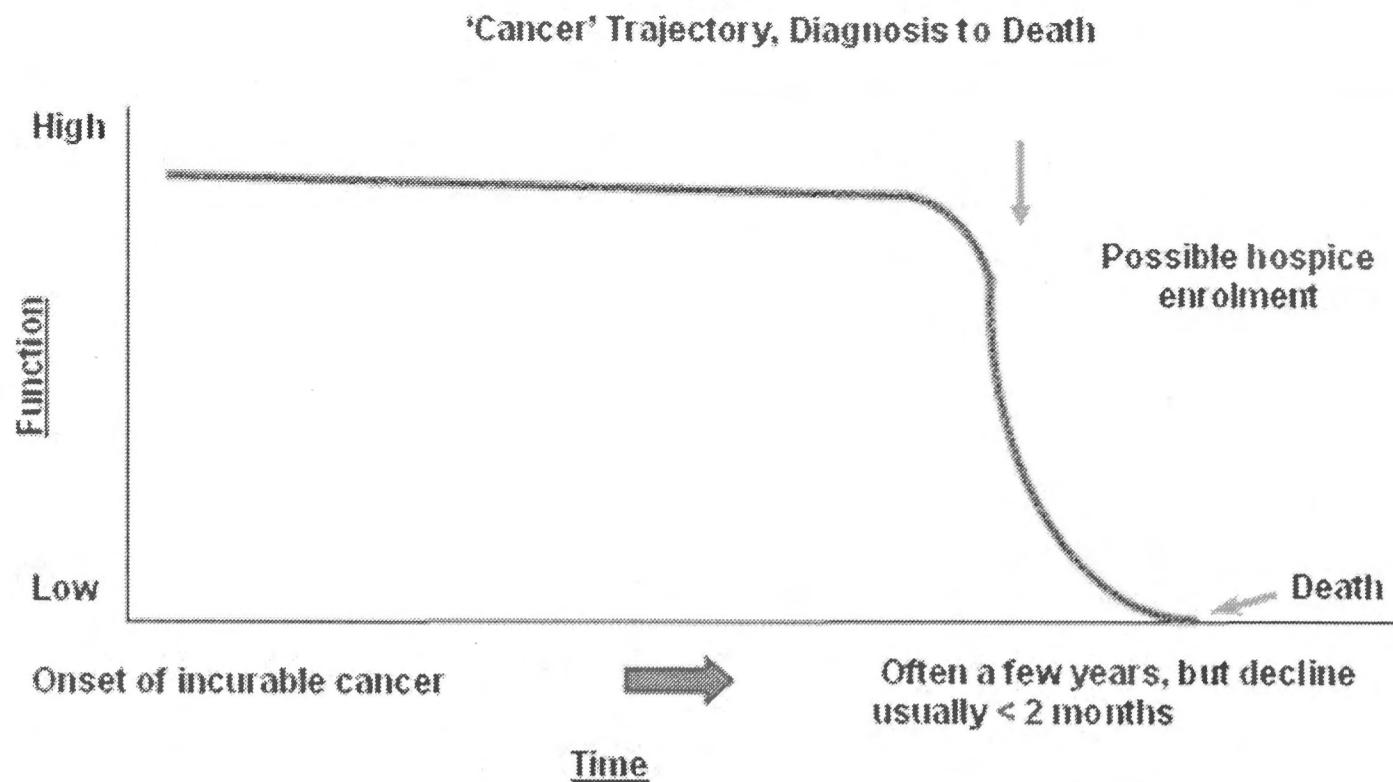
Families vacillated between feelings of helplessness and feelings of trying to steady their emotions so they could attend to the family. They wanted to protect their ill family member, but realise they were unable to control the ravages of an illness or impact the outcomes of the illness: 'We have no control. You can't do anything. We just sit there and watch or stand there.'²²

As we can see, unlike the patients, who are often ready to be driven to invent a new self by kicking an old habit or adopting a new health regime, their family members are driven to stay the same as they struggle to remain unchanged and emotionally steady. Indeed, emotional stability is the only means of holding a family together when, in reality, there is nothing anyone can do that will have an impact on the outcome of the illness.

However, Eggenberger and Nelms' study is restricted to the loved ones and family members of critically ill patients in the ICU, which implies a sudden decline in the patient's health during the course of the illness that the family members may not have predicted or prepared for (e.g. in an accident). For cancer patients, the course of illness is usually more predictable, which also impacts the ways in which family members *suffer with* the patient, both in terms of their lived relations and psychological space.

²¹ Sandra K. Eggenberger and Tommie P. Nelms, "Being Family: The Family Experience When an Adult Member is Hospitalised with a Critical Illness," *Journal of Clinical Nursing* (Vol. 16, No. 9, 2007), pp. 1622-3 (Italics original).

²² *Ibid.*, p. 1622.



The above graph illustrates a cancer trajectory from diagnosis to death. Its function is to estimate the physical, psychological, and social needs of the cancer patient from the point of prognosis onward.²³ Clearly, cancer patients typically experience a slow, gradual decline over a prolonged period of time that is followed by a progressive deterioration of health that inevitably leads to death. In particular, dying from cancer is usually not sudden. One can die quickly from heart failure or a non-functioning brain, kidneys, or liver, but death from cancer can be preceded by years of living with cancer and the requisite fear of recurrence and false alarms. Family members are thus given a relatively stable period of time during which to rebuild their life world after the initial diagnosis. In this rebuilding stage, family members often resort to seeking new information and knowledge about the disease and begin to discard anything that is not deemed useful as a way of stabilising their emotions and regaining a sense of control. Meanwhile, the “new” life is built on these new references, which serve as a guide to surviving cancer and preparing for the worst. Because one cannot simultaneously be hopeful and remain detached from life, this new life becomes

²³ Institute of Medicine, *Approaching Death: Improving Care at the End of Life*, 1997. Cited in Graves E. Enck, “The Dying Process,” *Handbook of Death & Dying Volume One*. Ed. Clifton D. Bryant (Thousand Oaks and London: SAGE Publications, 2003), p. 458.

constitutive of a larger social circle and set of activities through which a strong support network can be reinforced. The knowledge that they are actually *doing something* with other people allows family members to feel useful and hopeful. It may also become an impetus for the patients to feel hopeful about their own survival because, recalling Hatfield and Cacioppo's notion of "emotional contagion", seeing their loved ones' positivity typically forms a positive emotional feedback loop. In other words, we also need a wider and deeper sense of connection with life and living to sustain hope, such that, in a more pragmatic, everyday sense, life goes on. The hope of cancer patients and their families is essentially produced and sustained through a network of social and objective realities, as hope is involved in everyday life, in the here and now. And while there is no logical explanation of or clear definition for it, because of it, things can become different and strength can be found.

Images and the Dying of the Other

Our fear of death is driven by what we see and by its meaninglessness. As such, hope elevates us. It also allows us to be patient and flexible enough to wait for another vision to come when actions are impossible to fend off death. Imaginations are thus the seeds of hope. For example, when we can no longer hope that someone will be cured of cancer, rather than give up altogether we can adjust our hope by applying it to the next best thing that could happen, which requires the ability to imagine that second-best outcome. In the study conducted by Verhaeghe et al., one group of family members described being able to imagine spending Christmas with their ill loved one, who was in a deep coma, as what they needed to "go on".²⁴ Furthermore, hope plays a particularly crucial part in keeping the family and its life world together in situations where they are aware of the fact that the outcome is

²⁴ Sofie T. L. Verhaeghe et al., "The Process and the Meaning of Hope for Family Members of Traumatic Coma Patients in Intensive Care," p. 738.

unlikely to be positive. When faced with a loved one's dying, hope needs to adjust itself because in reality, there is nothing left to hope for.

Death becomes an emotional matter precisely because it is now a (nuclear) family matter. In fact, as I demonstrated in Chapter Four, the realities of cancer simply cannot be exclusively represented by pictures, numbers, or scientific facts. The "messiness" of dying and death is composed of what cannot be spoken directly because it can only be witnessed and experienced by family members and loved ones. Hence, intimate partners in particular play a more active role in cancer patients' quality of life than was previously thought.²⁵ This claim is also supported by Charles Corr's task-based approach to coping with dying, in which dying "is not merely a phenomenon that arises at the end of an individual's life; rather, it is a process that encompasses all of a person's life".²⁶ As such, dying is not about a single person, nor is it a singular event. Dying can no longer be viewed as a clean-cut matter or biological fact because there is always an ambivalent boundary between the living and the dying that extends from a personal experience into what Eggenberger and Nelms refer to as a "family experience":

The essence of this experience is the *family* experience as told by families as a whole, not simply individuals within a family. It is the *family* that experiences the gamut of emotions. Yet, it is *being family* and all that *being family* means to family members that makes them strong and able to endure and care about each other and their loved one. Even when relationships are torn because of the experience, they continue *being family*. Given that *being family* is what enabled families to endure the experience; it was therefore revealed as the constitutive pattern of the experience.²⁷

Echoing what Burgess refers to as the "emotional-supportive", which characterises the nuclear family, anthropologists Phyllis Palgi and Henry Abramovitch – in their

²⁵ For example, see Chris Segrin et al., "Dyadic Interdependence on Affect and Quality-of-Life Trajectories Among Women with Breast Cancer and Their Partners," *Journal of Social and Personal Relationships* (Vol. 22, No. 5, 2005), p. 675.

²⁶ Charles A. Corr, "A Task-Based Approach to Coping with Dying." Cited from Kent L. Sandstrom, "On Coming to Terms with Death and Dying: Neglected Dimensions of Identity Work," *Handbook of Death and Dying Volume One*. Ed. Clifton D. Bryant (Thousand Oaks and London: SAGE Publications, 2003), p. 469.

²⁷ Eggenberger and Nelms, "Being Family," p. 1625 (emphasis original).

research based on French historian Philippe Ariès' seminal work, *The Hour of Our Death* – also point to the fact that death has changed from a natural phenomenon to an emotive event due to changes in inter-personal relationships, especially after the appearance of the nuclear family:

With the nuclear family replacing the traditional community and the individual of the late Middle Ages, affectivity became concentrated on a very few persons whose disappearance caused a dramatic crisis: the death of the other... Under these changed conditions the fear of death was transferred from the self to the significant other. Simultaneously and gradually the belief in sin and hell began to weaken. The survivors now became the central figures, and they no longer mourned the fact of death but rather the pain of physical separation from the deceased.²⁸

This change in perceptions of death also explains why family members serving the dual role of caring for and coping with the prospect of losing the patient experience mixed feelings of regret and guilt when they see their loved one's suffering. Relative to how much stronger family relations are compared with those in the past, the family is now comparable to "a network of social obligation and affinity by other social networks based on friendship".²⁹ Relationships are precious, but fragile, and we are easily wrecked by regrets of having been withdrawn from a parent or a significant other or haunted by promises that we failed to keep. In other words, *their* death is *our* punishment and so, emotionally, we fear it.

To a certain extent, remaining hopeful while the loved one is dying requires that we rise above the chaotic and helpless situation and look for a way out, even if it is only through distancing ourselves from the difficult reality so that we do not have to be weighed down by guilt, regret, and other emotional burdens. To "rise above" a current situation also implies seeing a bigger picture, such that one's experience is not *in situ*. This applies not only to family members, but also to patients and anyone affected by cancer. We must look beyond what is there and make use of our

²⁸ Phyllis Palgi and Henry Abramovitch, "Death: A Cross-Cultural Perspective," *Annual Review of Anthropology* (Vol. 13, 1984), pp. 407-8.

²⁹ Daniel Miller et al., *Shopping, Place and Identity* (London: Routledge, 1998) p. 17.

imagination to escape cancer's terrifying grip, and our imaginings/imageries need not be relevant to what cancer really is. In contrast, they must be looking *the other way* for new meanings to be found.

Metaphors and Useful Images

Images must be processed via the imagination, and the more abstract the image, the more imagination it requires. In *Images of Hope*, William Lynch writes: "Despair lies exactly in the constriction of the private imagination."³⁰ For example, we do not know what death looks like, so use our imaginations to produce an image of it that will shield us from fear and despair. These images can come in many different forms and varieties and in Western culture the Grim Reaper and the Angel of Death are perhaps the most well-known. Ariès also addresses this need when he says: "Death loves to be represented."³¹ Undeniably, we have a natural curiosity and want to "see" cancer's face, understand how it works, and know how it "gets" us. This is perhaps also why we need to represent it. Hence cancer, like death, also loves to be represented, and as a result we have pictures, illustrations, graphs, and figures in textbooks; artwork and poetry created by patients; and academic writings about the cultural studies of cancer. As such, cancer is riddled by many contemporary images and invaded by metaphors.

However, unlike the Angel of Death, some metaphors/images of cancer are haunting precisely because they are partially true. As I mention in Chapter Two, we rely on metaphors and other images to serve as a buffer and create a linguistic distance between ourselves and reality; so much so that we rely on metaphors to more

³⁰ Lynch, *Images of Hope*, p. 23.

³¹ Philippe Ariès, *Images of Man and Death*, trans. Janet Lloyd (Cambridge, Massachusetts: Harvard University Press, 1985), p. 1.

or less define reality.³² Cancer metaphors and images fill in what we do not yet know and rescue us from what we are not ready to know. They protect us, even though cultural critics such as Susan Sontag and David Company argue that these images can hinder one's ability to think beyond the image or what is presented visually.³³

"Cancer is a war" is an example. We know that cancer is not war and that our body is not a war zone. Nonetheless, this metaphor has proven so resilient – at least throughout the last forty years – that it is no longer limited to Western English-speaking culture. One of the reasons for its great resilience is that it gives the patient hope and a sense of control over what can be done. It gives them the "vision" that their health lies in their own hands. Hence, the use of figurative language unintentionally shapes belief into something concrete that we can hold onto. It gives us hope. These are what I refer to as "useful" images.

Useful images are, and always will be, subject to constant attack and scrutiny because the portrayal of cancer patients as heroes runs the risk of masking other cancer realities such as fear, frustration, and despair. There are also images that are conducive to establishing a relationship between imagination and hope within cancer patients and their families. For example, a study conducted in the UK by Sue Morgan examines the effects of letting young cancer patients see their own cancer samples. Would it help them gain new knowledge or a sense of control over their illness? The result shows that while there is no significant improvement in knowledge or control, for these young adults actually seeing their own cancer improves their overall perception of the disease. According to Morgan's study, seeing their cancer sample through a microscope gives the young patients a sense of what they are up against.

³² For example, see George Lakoff and Mark Johnson's *Metaphors We Live By* (Chicago: University of Chicago Press, 1980.)

³³ David Company, "Safety in Numbness: Some Remarks on Problems of 'Late Photography,'" in *Where is the Photograph*. Ed. David Green (Brighton: Photoforum and Photoworks, 2003), pp. 120-132.

Such direct visual information (seeing what the doctors see) “empowers them as individuals and gives them ownership of their experience”.³⁴ Most of the young people in Morgan’s study also agree that knowing what cancer looks like – what colour it is or how it appears in the doctors’ eyes – actually makes the disease feel more manageable. Some patients even managed to change their opinions about cancer by no longer seeing it as “alien”, “dark”, “horrible”, or “ugly”.³⁵ In another study, also conducted in the UK, women with breast cancer are interviewed to see what kind of mental images they have of their illness.³⁶ The result indicates that these mental images change based on the patients’ views of their future during a particular stage of their illness – whether it is perceived with hope, reassurance, anxiety, or fear. The authors note that these mental images can also be used as a tool for researching patients’ illness beliefs, and that they do not have to be embodied exclusively in verbal form. In other words, these mental images help cancer patients find hope by using their own imaginations. For example, a patient might visualise her breast cancer as being as small as a pinhead to counterbalance her concern about the removal of fifteen lymph nodes.³⁷ We should note that the purpose of this use of imagery via visual metaphor is not to transcend or deny reality. It is to reduce the problem to a manageable size by changing its context and “state”.

Hence, guided imagery as a technique mentioned by Morgan and Harrow, et al. can be used for gaining control on the part of the patient and in cases when that is not possible, it can at least effectively reduce the patient’s psychological stress. How does guided imagery work in this context? The imagery and imaginings are

³⁴ Sue Morgan, “‘What Colour is My Cancer?’ The Experience of Teenagers and Young Adults Who Are Shown Their Cancer Samples Through a Microscope,” *European Journal of Oncology Nursing* (Vol. 13, No. 3, 2009) p. 180.

³⁵ *Ibid.*, p. 183.

³⁶ See Alison Harrow et al., “‘Seeing is Believing, and Believing’: An Exploration of the Meaning and Impact of Women’s Mental Images of Their Breast Cancer and Their Potential Origins,” *Patient Education and Counselling* (Vol. 73, 2008), pp. 339-346.

³⁷ *Ibid.*, p. 343.

“captured” like a snap-shot by the mind and then registered as being what cancer as an object looks like – overriding the reality that the object in question changes (grows/shrinks/moves/disappears/mutates) without our knowing. This helps the patient focus exclusively on the process and technique of visualisation as opposed to acquiring more information about the disease. Framed, stilled, and fixed, such images are useful and healing because patients can assert their power to act by “capturing” them in the mind and reducing cancer to powerless imagery. Similar to useful images, these mental images conjured by patients cannot directly capture the cancer reality and, to a certain extent, one might even argue that they distort it. For instance, cancer is not pink, nor does it in any way look like a pinhead, yet these images can imply a great deal about what we do not yet know about the disease. Recalling that hope potentialises a situation, in examples of guided imagery the imagination can be used as an alternative channel to hope that allows the mind’s eyes to see something different from the situation, particularly when all other channels are blocked.

The Happenings of Magic

As there are useful images, so we can assume that there are useless images. If images/imaginings/imaginings are useful because they give us a better understanding of the disease or visually inspire and thereby positively impact the patient, then those imaginings/imaginings that are deemed “irrelevant” to the current cancer discourse are “useless” and hence are never properly discussed in cultural studies. Nonetheless, they exist: perhaps in a novel about love, in a film about crime, or even in the thoughts of a person who has just lost someone to cancer. These untold imaginings are salutary to the repertoire of other (good or bad, useful or useless) cancer imaginings as the collective images that hold together all the

anomalous details that do not fit into what we currently know about cancer (perhaps due to the limits of our knowledge). However, like centuries of cancer discoveries, setbacks, victories, and death the way we see/feel/imagine the disease as patients/observers/readers/writers should also have a place in the cancer realities. “Useless” imaginings/imaginings can be freely disconnected from the reality of disease and the illness experience, thereby sustaining hope when there is nothing left to hope for.

Everyone must have hoped for a cancer-free world at some point, although the more accurate word would be to “dream” of such a world, knowing that it is unlikely. Nonetheless, we never stop seeking hope, even when we are under the direst privation. This is what Australian anthropologist, Ghassan Hage, calls the subjectivity of hope. In addition, there is also “societal hope” which, according to Hage, is “the capacities that societies have for the generation and distribution of social opportunities”. Hage clarifies that because societies do not distribute hope evenly and it can even be blocked, in such cases, “Millenarian hopes and fantastic dreams” such as lotteries or other games of chance serve as replacements.³⁸ In addition to religious faith and games of chance, I argue that there should also be yet one more kind of hope, something that is “magical”.

Magic is not necessarily “unreal”. Here, I will illustrate my point further with an example from the renowned science writer and biologist, Stephen Jay Gould, who was diagnosed with abdominal mesothelioma in 1982. At the time, no doctors were willing to advise him regarding literature about the disease. As a scientist, he searched the most current literature at the library by himself and was shocked by the

³⁸ Ghassan Hage, “Against Paranoid Nationalism: Searching for Hope in a Shrinking Society.” Cited in Galina Lindquist, *Conjuring Hope: Magic and Healing in Contemporary Russia* (Berghahn Books, 2005), pp. 8-9.

statistics and brutal facts: mesothelioma is incurable with a median mortality of only eight months after discovery.³⁹ Gould based his hope on the following rationale:

Attitude clearly matters in fighting cancer. We don't know why (from my old-style materialistic perspective, I suspect that mental states feed back upon the immune system). But match people with the same cancer for age, class, health, socioeconomic status, and, in general, those with positive attitudes, with a strong will and purpose for living, with commitment to struggle, with an active response to aiding their own treatment and not just a passive acceptance of anything doctors say, tend to live longer.⁴⁰

Gould was determined to find a way out of the statistics and he refused to believe that the eight months median mortality meant that he, too, would die in eight months' time. Because statistics on a curve are not inflexible, and choosing to believe that the variation around the means and medians is the only reality (that variation is nature's only irreducible essence) and the calculation of the median is only a form of abstraction, Gould decided to place himself in one of the variations. Variations mean that as long as the prescribed set of circumstances change, new distribution with a new median will emerge. Specifically, if we have a right-skewed graph such as Gould's, we must find our way to land ourselves not on the peak of the curve, but on the right side of the distribution. In the end, Gould lived for another twenty years, which means that he exceeded his eight-month median survival and was indeed living on the right side of the distribution.

Although this is not the only miraculous case in which a cancer survivor uses their will power to defy a "death sentence", Gould's case shows us that the "sentence" delivered by past empirical evidence used to calculate future cases is not necessarily valid and certainly cannot be considered the only means of predicting the future. This is an example way of a different way to give hope a concrete form is to put reality in the background, which places the hope of survival in the foreground. This

³⁹ Stephen Jay Gould, "The Median isn't the Message," first published in *Discovery Magazine* in June 1985 (see <http://people.umass.edu/biep540w/pdf/Stephen%20Jay%20Gould.pdf>).

⁴⁰ *Ibid.*

concreteness, rather than personifying or artistically representing, effectively changes what reality will become via one's action, which springs from one's imagination. It also implies that we can choose to see whichever reality we prefer to see, and that this is achieved by tricking our own minds like the working of magic.

Magic works wonders in ways that cannot be entirely anticipated or rationally planned. Magic is a tangible force that is present only during an interaction with the spectator through misdirection and optical distraction.⁴¹ A magician primarily produces a sense of wonder in the spectator. There are methods to ensure that the trick is achieved without the spectator understanding *how*. As much as it seems to defy the laws of physics and logical reasoning, there is actually nothing otherworldly about its effects. In a magic performance, we the spectators know that it is an optical illusion and yet everything about it is still real and tangible. For instance, there really is a deck of cards, a real pigeon, and a real coin. Even what (we think) we see is real, such that the magician really guesses the card correctly, the pigeon really flies from the magician's hat, and the coin really disappears from sight at the snap of the magician's fingers. Regarding why we tend to read statistics the wrong way, Gould believes that our Platonic heritage⁴² is the culprit. As Gould explains, although "nature often comes to us as irreducible continua",⁴³ our desire to find an unambiguous beginning of life and definition of death often leads us to emphasise definite boundaries and separated immutable entities. Likewise, our eyes are ready to categorise what we see according to the meaning that each specific action carries.

⁴¹ See Gustav Kuhn et al., "Towards a Science of magic," *Trends in Cognitive Science* (Vol. 12, No. 9, 2008) pp. 349-354 and Ronald A. Rensink et al., "To See or Not to See: The Need for Attention to Perceive Change in Scenes," *Psychological Science* (Vol. 8, No. 5, 1997) pp. 368-373.

⁴² According to Plato, object is essentially the "form". It is the perfect, unchangeable type without which a thing would not be the kind of thing it is. Form is the distinct singular object, whereas our sensual perceptions allow for plural representations of itself. They are the shadows mimicking the perfect form.

⁴³ Gould, "The Median Isn't the Message," (<http://people.umass.edu/biep540w/pdf/Stephen%20Jay%20Gould.pdf>)

Cognitively, we are not trained to escape from these boundaries into optical illusions where mirrors, lighting, and even our own eyes can produce make-believe phenomena. In Gould's case, however, hope was the magician that provided the magical lens through which to visualise the mutability of a graph. It worked like magic because it eluded theories.

Useless Images

It is time to question what we really hope to see regarding what cancer looks like. What possibilities can we hope for? If hope drives us to renew ourselves, can it also reinvent other imaginations to give rise to new collective forms of hope? If imagination can get people like Gould out of a dire situation by allowing him to see a line as something *else*, then what more can imagination do to alter what we think we know about cancer? What kind of hope can imagination produce? If hope enables a form of self-transformation for a patient, could a collective imagination transform the cancer reality? I do not attempt to answer these questions in this chapter, but I propose that hope should begin with "useless" imaginings, given the way we criticise their "useful" counterparts. Such imaginings are useless in the sense that they are neither conducive to producing new knowledges, nor do they, being anomalous, produce a cohesive text to read by themselves. To explain further, consider the following "useless" cancer images.

The Clink of Ice (Le Bruit des Glaçons) is a 2010 French comedy directed by Bertrand Blier. It begins when an alcoholic writer, Charles, is visited by his own cancer – a man of similar age, clad in a suit, who introduces himself by saying: "Hello, I am your cancer. I thought we should get acquainted." No matter how Charles tries to resist and kick this unwelcome guest out of his home, Cancer remains persistent. Interestingly, Cancer explains that only the person who is going to get that

cancer and the one who truly loves him/her can see Cancer. As the film progresses, we realise that the live-in maid, Louisa, also has a Cancer of her own (a female Louisa's age, dressed in black and resembling the Grim Reaper more than Charles' Cancer). Louisa can see Charles' cancer, but Charles cannot see hers. Throughout the film the audience sees how awkward their daily lives become with the two Cancers always nearby – even when Louisa (and her Cancer) eventually sneak into bed with Charles (and his Cancer) after Charles drinks himself unconscious. The title of the film (in both French and English) refers to the ice bucket that Charles carries everywhere, in which a bottle of white wine is always clinking against the ice cubes to chime the hours left in his empty, pathetic life, which is supposedly ending soon. Despite his imminent death, Charles does nothing to improve the health of his liver, or his health in general. Instead, he begins to welcome the charming and seemingly wise Cancer and its company. Together, they are always found “reminiscing about Charles' fall from grace, from being a loving husband and father to a reclusive, bitter has-been with a withering talent and penchant for doomed trysts with hot, young groupies”.⁴⁴ It is not until Louisa and Charles are sexually and emotionally involved with each other towards the end of the film that the audience begin to wonder how they are going to beat their respective Cancers and escape death. The film offers a solution: they fall in love with each another, fake their own deaths, and trick their Cancers into thinking they have committed suicide together. Eventually, the two Cancers are fooled and they leave to seek other potential victims.

In another version of cancer, novelist Jonathan Carroll's *The Ghost in Love* implies that cancer is more indiscriminate. Although the novel is not about diseases and none of the characters are suffering from any physical illness, cancer is

⁴⁴ Simon Foster, “Cancer Fantasy Falls Short in Final Moments,” *Film, SBS*
<http://www.sbs.com.au/films/movie/11012/The-Clink-of-Ice-> (Last accessed, 5 November 2011).

nonetheless included as part of the “danger” humans and animals alike encounter in their everyday lives and only certain species can see this particular danger with their naked eyes:

Cancer is pink; a pearlescent pink that moves swiftly and low to the ground like thin beautiful fog. Dogs have the ability to see it but cannot avoid being touched by it if their time has come. Like most animals, dogs can both see and smell diseases. They learn to recognize the differences between the deadly ones and the nuisances...

Almost to itself the Rottweiler muttered, ‘Cancer coming.’

‘I see it.’

‘Let’s hope it is not here for either of us’...

When the disease was a few feet away, the Rottweiler unconsciously took two slow steps back. ‘It must be nice being a human being and not have to see these things, you know? If you are going to get cancer, then just get it. You don’t need to see it coming down the street towards you and then climb up your leg. Damn. I hate this kind of suspense.’

‘Sssh, be still now,’ Pilot said quietly, kindly.

The mist drifted lazily past them and was gone. Both dogs drooped, their relief palpable.⁴⁵

Neither cancer in the form of a human avatar, nor in the form of a pink fog, brings us any closer to the reality of the disease. Neither reveals the meaning of the cancer experience, nor do they tell us how we should or should not feel about the disease. One film review of *The Clink of Ice* notes that although Death has appeared in human form in other movies such as *Meet Joe Black* and *The Seventh Seal*, the tone employed in *The Clink of Ice* is “pragmatically nasty tinged with camaraderie”.⁴⁶ In other words, the two Cancers are not villains trying to harm the protagonists, who are far from being cancer heroes themselves; rather, they are simply there to be seen/heard and, more importantly, to be intimidated. They are not horrifying, evil, or even ugly. There is nothing to love or hate about these cancers in human form, and

⁴⁵ Jonathan Carroll, *The Ghost In Love* (New York: Crichton Books, 2008), p. 74.

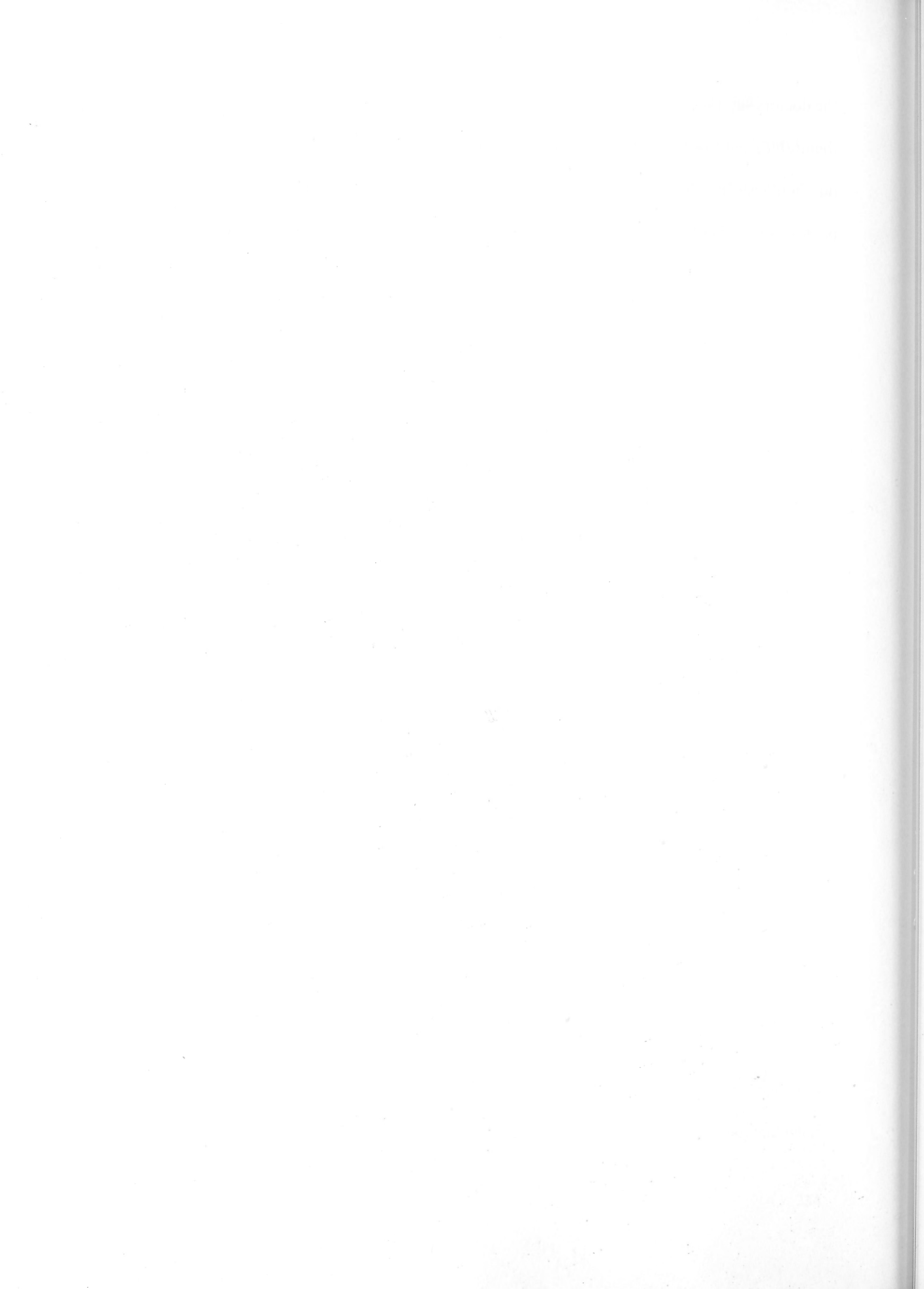
⁴⁶ Lisa Nesselson, “The Clink of Ice (Le Bruit Des Glaçons)” *ScreenDaily* (Aug 25, 2010) <http://www.screendaily.com/reviews/latest-reviews/-the-clink-of-ice-le-bruit-des-glaons/5017308.article> (Last accessed 5 November 2011).

they pose a question: Would we be more grateful if cancer could announce its presence in the form of a morbid visitor that can only be seen by someone who truly loves us? Similarly, in *The Ghost in Love*, there is nothing to prove or disprove Carroll's description of cancer because we are not privileged in the way that canines are. Because we as readers do not have to identify with cancer patients (there is no cancer patient anywhere in the story), "cancer" is given a very neutral image that eludes any theories. As with magic, it is not about what we see being right or wrong. Magic is simply magic. We think we see something happening, but we also know that it did not happen the way we "saw" it happen. Even if something appears to defy gravity, the laws of thermodynamics, or quantum physics, it is only because we are able to imagine the chain of events as possible and are willing to suspend our logical and cognitive reasoning. These images point to their "uselessness" not because they fail or are a mistake, but because we cannot add to our knowledge of cancer by looking at them. They are "useless" because they do not fit within the metatext of cancer and can only exist somewhere else – further away from metaphors this time – in the realms of farce and magical realism, respectively.

In conclusion, I once again refer to Lynch's comment that hope "not only imagines: it *imagines with*".⁴⁷ In a theological context, Lynch means that hope must in one way or another be an act of a community, such as that of a church, but it can also be taken to mean that people can create hope together and that hope can be something that people "play with" and co-imagine collectively. The life of hope is the life of imagination because the act of imagining connects uncertain futures with options, which suggests that without imaginations as a way out, individuals will not be as able to conjure possibilities for the future. Therefore, for most cancer patients and their families, imagination broadens what is possible by taking them beyond what

⁴⁷ Lynch, *Images of Hope*, p. 23.

the doctors say for a glimpse of the bigger picture – as long as they can lift themselves and rise to greet the situation. Being able to imagine what previously was not there – seeing channels such as possible exits, secret entrances, and hidden passageways – is just as precious to the hopper.



Chapter Seven – The “Heart” of Traditional Chinese Medicine

In this chapter, I focus on traditional Chinese Medicine (TCM) and argue that while it may not be the answer to what conventional medicine cannot do, it nonetheless offers a more complex system in which healing, much like everything else in life, is open to chance and circumstance. This introduction will help decentre us away from the scientific reasoning of biomedicine and present other possibilities for understanding a disease such as cancer. As such, I do not concentrate on answering the question of what TCM is – its mechanism or epistemology – and instead examine how it affects our understanding of nature and the human body, particularly how one is used to complement the other, to shed light on why TCM is generally believed to be more “natural” and “holistic” than biomedicine. I also examine how TCM garnered its fame among its Western biomedical counterparts as the maker of clinical miracles, particularly in “hopeless” cancer cases that do not respond to biomedicine.

I begin by analysing the relationship between the natural landscape and the Chinese concept of *Qi* (the “breath of life”) to illustrate how nature is visualised as alive and changeable. Because the Chinese concept of holism is based on a non-dualism between nature and culture, I also argue that holism is, in the Chinese medical sense, an art of interpretation and creation on the part of humans to unite mind and body. This explains why both nature and the human body are treated as “one unity” within the Chinese way of thinking. This focus also allows us to explore the so-called, non-mainstream medical perspectives of health and illness, particularly those that exist outside the causal, linear, and reductionist thinking systems that characterise biomedical science.

I then turn to the idea of what Ted Kaptchuk calls, “the human landscape”, to explain how the human body, as it is understood in traditional TCM, is not the simple sum of one’s anatomical parts. This naturally leads to an anti-perspectival view of the human body, health, and illness that is most obvious in the fact that the human organs in TCM are not considered to perform the same functions as they do in Western medicine. Likewise, their relation to health and illness is different than it is in biomedicine. As such, the human body is best illustrated by a metaphorical human landscape as we explore the significant role that the figurative “Heart” plays in TCM.

Furthermore, because TCM operates on the belief that our bodies are composed of Zang-fu organs and subject to the Meridian system, and that our being is sustained by *Qi* and benefits from the balance of *Yin* and *Yang* to create a harmonious environment, I argue that the interpretation of the human landscape is inseparable from how nature is represented and understood. Using the famous *Summer Mountain Painting* as an example and analysing its unique arrangement and composition, I draw a parallel between spiritual cultivation in the act of natural landscape appreciation and the holistic view of the human mind and body. I also reveal how, through the anti-perspectival view of nature most commonly found in Chinese landscape painting, the human body becomes part of nature, such that health and illness can be placed within a wider context that is charged with meanings derived from our everyday experience.

Finally, I use ethnographer Mei Zhan’s case studies on the practice of TCM as conducted in Shanghai and San Francisco to further her argument about what makes clinical “miracles” possible in TCM.¹ Much like the nature of cancer, which must be placed outside the biomedical lens to obtain a more comprehensive picture, the fact that TCM cannot be explained by medical science is what defines its practice. The

¹ Mei Zhan, *Other-Worldly: Making TCM through Transnational Frames* (Durham and London, Duke University Press, 2009).

term “miracle”, which we sometimes use to characterise what TCM can achieve, only highlights how incapable we are of including what lies outside the biomedical and scientific rationality in our system of thinking. It is only when we place TCM inside a more complex system beyond the boundary of Western science and biomedicine (as opposed to being at the centre of the biomedical arena and subject to speculation and examination) that can we recognise that healing, much like everything else in life (accidents, failures, luck), is aleatory, open to chance, and circumstantial.

Alternative Medicine and the Natural Landscape

The natural landscape commands a different status in TCM than in biomedicine. First, I need to clarify what TCM means and how it should be understood throughout this chapter. TCM literally refers to medicine and all therapeutic activities as practised in China, the practice of which has a long history that exceeds two-thousand years. The first systematic document of its medical theory can be found in the *Huang-di Nei-Jing* (“the Emperor’s ancient medical text”)². Nonetheless, present-day TCM is no longer confined by its geography, culture, or language, nor is it only practised by ethnic Chinese. Unlike many indigenous medicines that have been displaced by Western science in the past three to four hundred years, TCM has become a popular, licensed avenue of treatment, particularly for diseases that biomedicine seems to treat less effectively or even ineffectively – both in the East and the West. These days, going to an acupunctural clinic has become part of a “hip, middle class, cosmopolitan lifestyle that emphasises overall well-being and mid-body health”, and acupuncture has been reinvented as a holistic, preventive medicine practice, both within China and throughout the West.³ In most

² Huang-di Nei-jing (皇帝內經) is an ancient medical text believed to have been written over 2,000 years ago by Huangdi (the Yellow Emperor) and his ministers. The book is built on the concept of a dialogue between Huangdi and his doctor and remains the most important text in the canons of TCM and the practice of Daoism.

³ Mei Zhan, *Other-Worldly*, p. 14.

Western societies including Australia and the US, herbalism, aromatherapy, homeopathy, acupuncture, massage, reflexology and similar treatments fall under the category of complementary and alternative medicine (CAM). The National Centre for Complementary and Alternative Medicine (NCCAM) in the US defines CAM as “a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine; that is, medicine as practiced by holders of ‘medical doctor’ or ‘doctor of osteopathy’ degrees and their allied health professionals, such as physical therapists, psychologists, and registered nurses”.⁴ Although the definition used by this particular US government agency is deeply embedded in the Western scientific discourse, which renders everything outside of itself “non-conventional” and “unscientific”, this is also how CAM is understood – as different from the mainstream and through its identity as the *Other*. Likewise, TCM is also constructed through what it is *not*.

“Alternative” medicines have long been recognised as a low-cost, low-tech, but effective way of treating diseases in “non-Western” parts of the world. The term “alternative” usually refers broadly to what is not biomedical, which can range from local witch doctors, to medical practices that are not based on the rationale of Western science, to the use of medicinal meals and/or spells. Although at times these “alternatives” are dismissed as plain quackery, they are becoming more and more acceptable in Western societies and are sometimes even extolled as more “natural” and holistic in their healing – if only to the local indigenous people. Barcan and Johnston aptly remark that the cultural study of alternative medicine is a useful lens for us to understand contemporary shifts in value and belief (in Western societies). Particularly, alternative therapies are implicated in “a reaction against the perceived

⁴ National Centre for Complementary and Alternative Medicine (NCCAM). (Source: http://nccam.gov/news/camsurvey_fsl.htm) Accessed 10 May 2011.

rationalism of late modernity (including both a nostalgic yearning for a supposedly "simpler" and more "natural" past and a utopian longing for a redemptive future)".⁵

This is most notable in how such alternatives are portrayed in Western popular culture. Consider the 2009 Hollywood epic science fiction film, *Avatar* (Dir. James Cameron). This box office hit uses computer-generated imagery (CGI) to create a 3D "landscape of healing" on a fictional planet called Pandora. Scattered around the planet is a precious mineral called unobtainium that is valued at "20 million a kilo". The humans are mining it out of greed and their mining colony is threatening the existence and peaceful lives of an indigenous tribe of beings called the Na'vi. Protagonist Jake Sully (played by Sam Worthington) is the hero of the film and in the end, he saves the local tribe from total destruction at the hands of his human counterparts. The conquered, humiliated humans are forced to return to their "dying planet" while Jake becomes one of the humanoid Na'vi and stays with their Princess, Neytiri, and her people. In addition to the highly profitable mineral, the planet is also filled with the spirit of Eywa, the Divine Mother of the Na'vi, and the wealth of bioluminescent species and exotic fauna and flora that crowd the vertiginously suspended forest landscape. Most notably, a sacred, giant tree known as the "Home Tree" plays a central role in this fictional space. Healing occurs when the Na'vi perform a ceremony that includes praying collectively under the Home Tree. In this ceremony, the Pandoran ecology forms a vast neural network spanning the entire planetary surface through which the Na'vi and Pandora's creatures can connect. Throughout the film, scenes show how the Na'vi use the long braids protruding from the backs of their heads to feed directly into the brains of each other and the planet's creatures, which appears to allow electro-chemical signals in the form of thoughts and memories to be transferred, thus creating a connection not only with one another,

⁵ Ruth Barcan and Jay Johnston, "The Haunting: Cultural Studies, Religion and Alternative Therapies," *Iowa Journal of Cultural Studies* 7 (Fall 2005), p. 66.

but also with the other organisms that share the planet. *Avatar* depicts Pandora as not only exotic and futuristic, but also indigenous, spiritual, and sacred. The film appeals to the mass public precisely because it stands as the ultimate Hollywood imagination of a self-enclosed, self-sufficient, ecological system that is far enough away to be unpolluted by “modern” people with advanced technology. This pure ecosystem also embodies the multidimensionality of healing: biological, spiritual, emotional, and social (communal).

It is only recently that health geography has begun focusing on the role of therapeutic landscapes in shaping health by recognising the meaning of place. The relationship between place and health is culturally specified. For example, land, as place, is specifically important to the Anishinabek people (a tribe of original inhabitants living in northern Ontario, Canada). As Kathleen Wilson points out, land represents more than just the physical space in which the Anishinabeks’ daily lives are experienced. Through their association of land with the image of Mother Earth, it becomes connected to individuals not only physically, but also symbolically and spiritually.⁶ Similarly, the Aboriginal people of Arnhem Land, located in Australia’s Northern Territory, do not have the same social and health problems as those who live outside of it. Reports such as those conducted by Amnesty International also claim that Aboriginal people living in homeland communities are less likely to be involved in substance abuse, poor eating habits, and violent behaviour because they maintain their traditional lifestyle away from the influence of the big towns.⁷

Interestingly, both *Avatar*’s primary actress, Sigourney Weaver, and its director, James Cameron, are outspoken activists for the preservation of the natural habitats of

⁶ See Kathleen Wilson, “Therapeutic Landscapes and First Nations Peoples: An Exploration of Culture, Health and Place,” *Health and Place* (Vol. 9, No. 2, 2003) pp. 83-93.

⁷ For example, see <http://www.creativespirits.info/aboriginalculture/land/aboriginal-homelands.html#ixzz1fcCyBdMh> or <http://www.amnesty.org.au/indigenous-rights/comments/26139> (Last accessed 10 December 2011).

the indigenous peoples and species of the Amazonian Rainforest (the inspiration for Pandora's biodiversity). The adverse effects that the construction of the Belo Monte Dam Complex would have on the Rainforest drove Cameron to make the following public statement:

Here were people whose lives were going to be altered irrevocably, whose communities were going to be destroyed, literally put under water, or affected negatively as the river's flow would change. For these people, it's the end of their world, as they know it.⁸

Avatar is successful because its temporal and geographical distance places it between fiction and reality. Thus, we (those who are not affected by the development in the rainforest) can sit back and watch how the colonising humans, driven by greed and caught up by globalisation and capitalism, trample the Na'vi lifestyle – all from the moral safety of the big screen. *Avatar's* utopic filmic representation of a “perfect future planet” is reminiscent of the pursuit of the Platonic idea of beauty. Plato saw everything in the physical world as a mimic or a copy of an objective standard – an ideal form – such that the more an object in reality approximates this ideal form, the closer to perfection it is.⁹ In *Avatar*, the audience can make a connection between the “ideal” form of healing and the indigenous forms of knowledge and lifestyle in which the ideal – the utopia – is always imagined as “elsewhere”. It is no coincidence that in the real world, we are also trying to mimic this ideal form. We yearn for this “elsewhere” because it is different from the daily environment we find ourselves in and, most importantly, the perfect form suggests that there is a “formula” for a perfect copy out there – as long as all the right parts are properly combined as a whole.

⁸ Cited from “Sigourney Weaver, James Cameron Fight Amazon Dam Project,” *Mother Nature Network*, <http://www.mnn.com/lifestyle/arts-culture/blogs/sigourney-weaver-james-cameron-fight-amazon-dam-project> (Last accessed 14 December 2011).

⁹ See “Plato's Aesthetics,” *Stanford Encyclopedia of Philosophy* (First published Jun 27, 2008).

TCM is an interesting case in point because it is based on the “long-term observations of human physiological and pathological phenomena in addition to the influence of natural conditions on the human body”.¹⁰ The medical practices and metaphorical belief systems inherent in TCM are greatly influenced by Taoist principles, which serve as a foundation for the concept of holism. It is therefore portrayed as an “ideal” form of holistic healing that combines ancient knowledges of geomancy, philosophy, spirituality astronomy, and geography. It is the “elsewhere” modern societies yearn for, but does TCM, like *Avatar*, represent a distant space and time, or is it like other indigenous medicine that must be rooted in its homeland, such that to copy its form one must speak the language or read its medical texts? Must we interact with its natural space, and if so, what space does TCM occupy? According to the *Nei Jing*, TCM’s idea of holism refers to the integrity of the human; that its various bodily functions should be kept balanced and harmonised, which can only be achieved through the unity of man and nature. Hence, when we talk about TCM, we are not just looking at how an illness affects the body and how it can be treated, we are considering the “whole picture” of a mind-body-nature unity and how to maintain or regain its balance and harmony.

Within this concept of holism, nature and the body, including its organs and tissues, are all closely related and indispensable to the whole, which is composed of and sustained by *Qi*. *Qi* is the “vital energy” or “breath of life” at the core of TCM and Feng Shui (geomancy). According to Taoist principle, everything in nature can be categorised into *Yin* and *Yang*. *Yin* and *Yang* should not be perceived as forces or material entities, but rather as two opposite facets that only exist in relation to one another. Regarded as the Chinese concept of creation that gives rise to the

¹⁰ *A General Introduction to Traditional Chinese Medicine*. Ed. Men Jiuzhang and Guo Lei (Boca Raton: CRC Press, Taylor & Francis Group, 2010), p. 18.

phenomenon of the world, *Yin* and *Yang* are comparable but not equivalent to Western binary concepts such as male and female, night and day, and hot and cold. Unlike the mutual exclusivity of most Western binary concepts, *Yin* and *Yang* mutually create and transform each other as illustrated by the *Yin-Yang* symbol – each swirling around the other as a sign of mutual dependence while simultaneously infusing one another to create a whole system.¹¹ When *Yin* and *Yang* are balanced, the flow of *Qi* is not impeded and harmony is achieved. Similarly, *Qi* is not, and should not be, understood merely as a form of physical energy such as electricity or magnetism, because it does not have an objective existence. It is, by definition, a “cosmic spirit that vitalises and infuses all things, giving energy to human beings, life to nature, movement to water and growth to plants”.¹² Thus, it is regarded as the one component of the universe; the keeper of harmony among Heaven, Earth, and humanity that provides an equilibrium among nature, the living environment, and the people who inhabit it. Although *Qi* cannot be seen or felt, it can be enhanced or impeded depending on how things are organised and arranged in relation to their *Yin-Yang* manifestation, thereby inducing harmony or enhancement within the equilibrium of things (mind-body-nature). This also means that while how much *Qi* an individual has is a pre-given, how it is distributed is a matter of knowledge and art.

How *Qi* and *Yin-Yang* are applied in the appreciation of the natural landscape best reflects the knowledge and art required to achieve mind-body unity according to TCM. As previously mentioned, present-day Western representations of nature usually reflect it as being the way it is with the suggestion that the work of nature should be untempered by human creation. For instance, the Grand Canyon and the

¹¹ See Larry Sang's *The Principles of Feng Shui*. Trans. Helen Luk (California: The American Feng Shui Institute, 1995), p. 10.

¹² Stephen Skinner, *The Living Earth Manual of Feng-shui Chinese Geomancy* (London: Arkana, 1989), p. 19.

Twelve Apostles are “naturally” and “historically” preserved. In other words, their beauty is not materially altered by human exploitation and occupation. Rather, it comes from the way they naturally are.¹³ In contrast, scenic areas are famous for being “works of man rather than geologized processes” in the Chinese landscape.¹⁴ Using the famous West Lake in Hang-chou, China, as an example, Yi-fu Tuan explains that it is the way in which human works can blend in within nature’s frame that marks the significance of a Chinese landscape:

Hang-chou’s West Lake, for example, was celebrated by T’ang and Sung poets and it remains to this day an adornment of China. To the casual visitor, the West Lake region exemplifies how human works can blend modestly into nature’s magistral frame. But the pervasiveness of nature is largely an illusion created by art. Some of the islands in the lake are actually man-made... Hang-chou’s environs, then, owe much of their calm harmonious beauty to human design and effort.¹⁵

Such human design and effort is most important in enhancing the harmony between nature and mankind. The same concept is unsurprisingly also practised in Chinese geomancy, or Feng Shui – the art of discovering the places where *Qi* is present to ensure a “calm harmonious beauty” within a given site. For instance, from selecting a burial site or designing a city or the interior layout and orientation of a corporate building to building a new house, a geomancer will find ways to conform to theories based on the observation of astronomical phenomena, natural phenomena, and human behaviour. For example, *Qi* travels and disperses with the wind but is retained in the presence of water. If a particular site is not considered suitable or favourable, a geomancer will suggest adding an element (such as a pot of water plants or a tank of goldfish) to enhance the flow of *Qi* and improve the liveliness of the site. A geomancer will also suggest removing offending objects (such as misplaced mirrors)

¹³ It should be noted that the discourse of nature has shifted throughout Western history. With the rise of the environmental and climate change discourse, the discourse of historical/heritage preservation has become more prominent.

¹⁴ Yi-fu Tuan, *Chinese Attitudes to Nature: Ideas and Reality* (Canberra: Australian National University: 1976) p. 6.

¹⁵ *Ibid.*

that impede the flow of *Qi*. In cases where the site is deemed inauspicious but there is nothing that can be done to alter it, a search for a different site will be recommended.

This employment of human organisation to make a natural landscape calm and harmonious to deliver a better mind-body experience cannot simply be placed alongside the perspectives of physical science, religion, philosophy, aesthetics, or even sociology. The best way to make sense of it is to think of the concept of nature metaphorically. Again, to use Feng Shui as an illustration, according to its classic text, entitled *Zangshu* (the Book of Burial),¹⁶ Feng Shui studies the changeability of the relationships between the forms and forces in nature to promote its liveliness. This is represented by the symbolic meanings of “wind” (Feng) and “water” (Shui). Indeed, natural phenomena are understood metaphorically to open a new way of interpreting nature. For example:

The beginning and end of geomancy is nothing more than the layout of mountain ridges and all the authorities are alike in referring to them as dragons. Why is this? Because none but the magic dragon can lie low or fly and be big or small; and the earth's forms may rise to mountain heights or fall away to deep springs... The magic dragon writhes and changes, unknowable in its subtle origins; and mountain ridges that have life breath will start to run east then suddenly turn west, or begins to run south then suddenly head north; you cannot pin them down – off they go in all directions.¹⁷

The above passage not only shows that landscape is alive and changeable, but also represents “the inexhaustible succession of divine impressions the mind experiences in landscape”.¹⁸ Whether in a natural or built environment, such personification or animation of the layout of the natural landscape tells us that we – ourselves and nature – are also mutually creating and transforming each other. Thus, it is not only

¹⁶ See *A Translation of the Ancient Chinese: The Book of Burial (Zang Shu) By Guo Pu*. Trans. Juwen Zhang (Michigan: E. Mellen Press, 2004).

¹⁷ Andrew L. March, “An Appreciation of Chinese Geomancy,” *The Journal of Asian Studies* (Vol. 27, No. 2, Feb 1968) pp. 256-7.

¹⁸ *Ibid.*, p. 257.

what humans can do in nature, but also what we do *with* it. This is most obvious in the design of private or miniature gardens in China:

When we come down to the small compass of the private garden the illusion of pervasive nature is far more difficult to achieve. Nevertheless the Chinese gardener strives to achieve it with cleverly placed water-worn limestone the jagged outline of which suggest wildness, and he does it by means of winding footpaths that give the stroller an illusion of depth and space. In this line, Oriental man's ultimate triumph lies in the miniature garden, where wild nature is reduced to the scale of a dwarf landscape that can be fitted into a bowl.¹⁹

Tuan's observation suggests that the beauty of nature is not about its vastness or the natural wonders it contains. These miniature gardens, designed exclusively for the individual's pleasure, actually signify the triumph of human creation and its ability to make nature more comprehensible and personal. What is noteworthy in this re-creation and "reduction" of nature's size is that it suggests that the Chinese appreciation of the beauty of nature is a process of incorporating one's spiritual wellbeing without having to be physically away from home or work (that is, the everyday life). Moreover, there is no longer any dichotomy between what is man-made and natural through this re-creation. As such, we now turn to look at how the human body is related to nature in terms of representation and interpretation.

Human Landscape

In TCM, the human body, along with health and illness, is understood as a system composed of Zang-Fu organs and the Meridians. Like the natural landscape, the functions of both Zang-Fu and the Meridians are based on the same principle of *Yin-Yang* balance and the flow of *Qi* used to explain and interpret the phenomena of nature. "Zang" organs include the Heart, Liver, Spleen, Lungs, and Kidneys²⁰ and are considered *Yin* in that they are responsible for producing, transforming, regulating,

¹⁹ Tuan, *Chinese Attitudes to Nature*, p. 6.

²⁰ I capitalise these organs to specify their difference from the biomedically defined organs we usually associate with in the human anatomy.

and storing the body's fundamental texture: *Qi*, blood, essence, spirit, and fluids. "Fu" organs include the Gallbladder, Stomach, Small Intestines, Large Intestines, the "Triple Burner",²¹ and the Urinary Bladder. These are considered *Yang* organs because they "receive, break down, and absorb that part of the food that will be transformed into fundamental textures, and transport and excrete the unused portion".²² Zang-Fu organs are linked to the body's skeletal frame (the limbs, head, face, and trunk) through the Meridian system.

The Meridian system is "a network where viscera, sensory organs, orifices, skin, five constituents [a concept that includes tendons, vessels, muscles, skin, and bones] four limbs, and all the skeletal parts are connected".²³ It functions as a channel through which *Qi* and blood circulate. As a result, a disorder of a Meridian can generate derangement in the pathway that creates disharmony along that organ. Or, if something is wrong with the Meridian's connecting organ, then there is a derangement in the Meridian's pathway. As such, the human body is not understood in anatomical terms that characterise the body into different internal/external parts. In biomedicine, the body's anatomically divided parts are "assigned" respective specialised biomedical units such as cardiology for the heart, renal services for the kidneys, gynaecology for the female reproductive organs, or the endocrine department for the hormones. TCM considers the body as a whole in the form of a human landscape:

As an organic integrity, parts of the human body are inseparable in structure, coordinative in physiology, and mutually interacting in pathology. Meanwhile, the unity of the human body and nature lies in the fact that the human body is influenced by the natural conditions and therefore human beings have to adapt to nature to maintain their normal vital activities.²⁴

²¹ The Triple Burner is a collective term for the parts of the human body responsible for our metabolism. These parts include the thoracic cavity and the upper- and lower dorsal cavities.

²² Ted Kaptchuk, *Chinese Medicine: The Web That Has No Weaver* (London: Rider, 2000) p. 78

²³ Men and Guo, *A General Introduction to Traditional Chinese Medicine*, p. 39.

²⁴ *Ibid.*, p. 38.

The theories of *Qi*, *Yin-Yang*, and the Meridians are the conceptual basis of TCM, but they are not represented by any scientific theory familiar to the West, which means that they cannot be subjected to the biomedical lens for investigation. They also cannot be proven through the double-blind and replicable experiments that Western science is based on. Interestingly, within the Zang-Fu visceral system, names such as “Heart”, “Liver”, “Spleen”, “Lungs”, and “Kidneys” are merely a result of the translation of biomedical terms into Chinese. As they are understood in TCM, they do not reflect modern anatomical terms and their significations or correspond to the biomedical anatomical parts of the body.²⁵ Rather, they are best viewed as symbolic or functional.²⁶ It is precisely because the human landscape is meant to be symbolic rather than anatomical that the concept of health and illness must be placed within the wider context to have any meaning or significance. To understand how the human landscape can be interpreted metaphorically, it is useful to turn to the anti-perspectival aspect and the temporal quality that characterise Chinese landscape painting for more insight.

The Chinese characters for landscape painting (Shan-shui Hua) literally mean “Mountain River Painting”.²⁷ Mountains are often used to signify a tranquil and sober atmosphere. In her discussion of the influence of Taoism and Buddhism on Chinese landscape painting, Miranda Shaw remarks that mountains are the link between Heaven and Earth, and “these mountains were considered to be auspicious because they contained an abundance or propitious configuration of [*Qi*].”²⁸ Mountains are usually accompanied by rivers, which are a symbol of liveliness, alertness, and resourcefulness. Together, these two elements are the most active and

²⁵ See Ted Kaptchuk’s *The Web That Has No Weaver* and Volker Scheid’s *TCM in Contemporary China: Plurality and Synthesis* (Durham: Duke University Press, 2002).

²⁶ Zhan, *Other-Worldly*, pp. 76-77.

²⁷ Mountain River painting is a direct from the Chinese characters 山水畫.

²⁸ Miranda Shaw, “Buddhist and Taoist Influences on Chinese Landscape Painting,” *Journal of the History of Ideas* (Vol, 49, No. 2, Apr-Jun 1988) pp. 191-2.

perfect embodiments of the universe and of *Yin* (rivers are considered yielding) and *Yang* (mountains are considered dynamic). Therefore, when visually representing Chinese landscapes, mountains and rivers are always present. Under the influence of ancient Taoist belief, being natural is extolled as the highest form of spiritual cultivation. It is a personal journey and communication with nature through which the literati can refresh the mind, meditate, seek alchemical herbs, and engage in refined pastimes.²⁹ In a similar vein, such spiritual communication can be re-enacted when viewing a landscape painting. The viewer is invited to physically and mentally move within and across the painting. Among the different styles of landscape painting, scroll painting, which prospered during the Sung Dynasty (A.D. 962-1279), is an archetype that “depict[s] the vastness and multiplicity of creation itself”.³⁰ To begin this visual journey, the viewer starts at the right and moves their gaze to the left as they un-roll the painting (see Figure 1).



(Figure 1)³¹

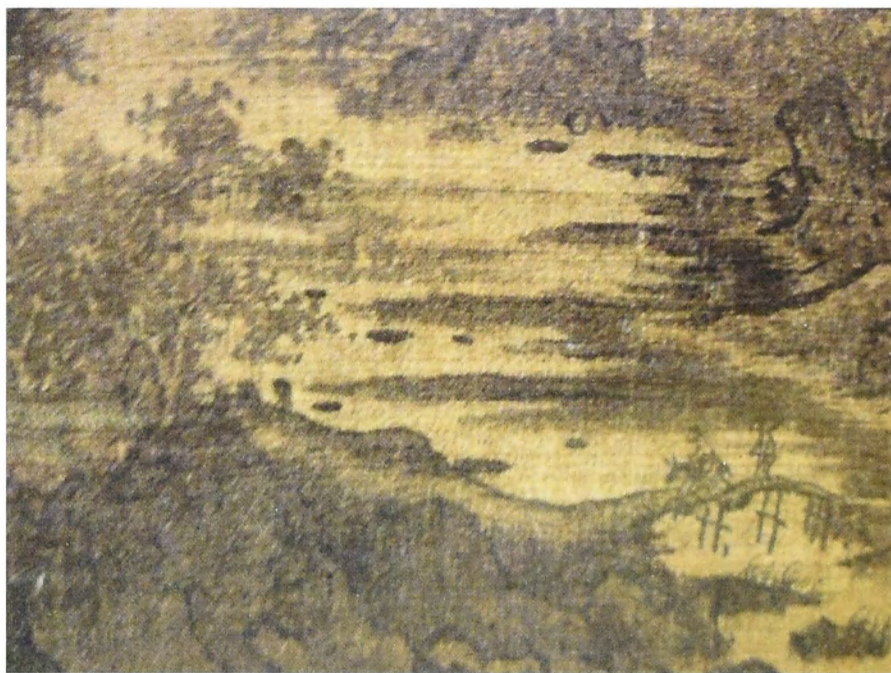
Entitled “Summer Mountains”, this painting is one of the most important art pieces from the South Sung Dynasty.³² Taken as a whole, it invites its viewers to

²⁹ *Ibid.*, p. 190.

³⁰ Maxwell K. Hearn, *How to Read Chinese Paintings* (New Haven and London: Yale University Press, 2008), p. 20.

³¹ <http://www.fineart-china.com/htmlfindCN/tw/artist-0000449.html>

“travel” from right to left with their eyes. Beginning with a view of the sky, the distant mountain ranges, and the river from afar, the mountains grow larger and sit commandingly at the centre, “like an emperor among his subjects, the culmination of nature’s hierarchy”.³³ This echoes the image, common in Feng Shui, of mountain ranges as “magic dragons” harnessing energy above the mere “mortals” below. As Figure 2 illustrates, our journey begins with the traveller on his donkey in the lower right corner:



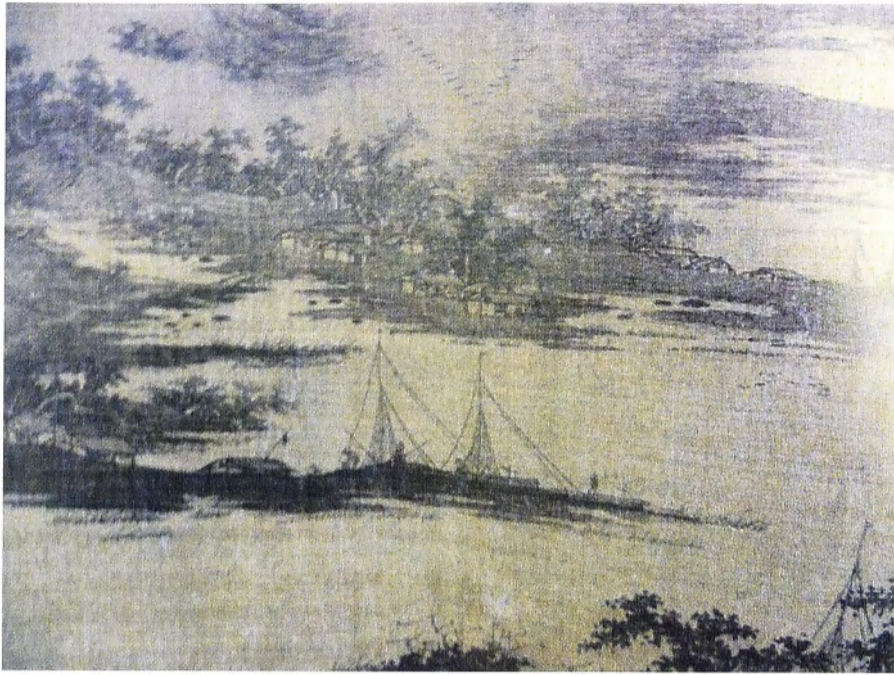
(Figure 2)³⁴

We cross the river and encounter some fisherman who appears through the summer mist (Figure 3).

³² For the purpose of my analysis, the original painting has been broken into parts to better illustrate the details being discussed. Figs. 4 - 7 are taken from Maxwell K. Hearn’s “The Vastness and Multiplicity of Creation” in *How to Read Chinese Paintings*, p. 20-27.

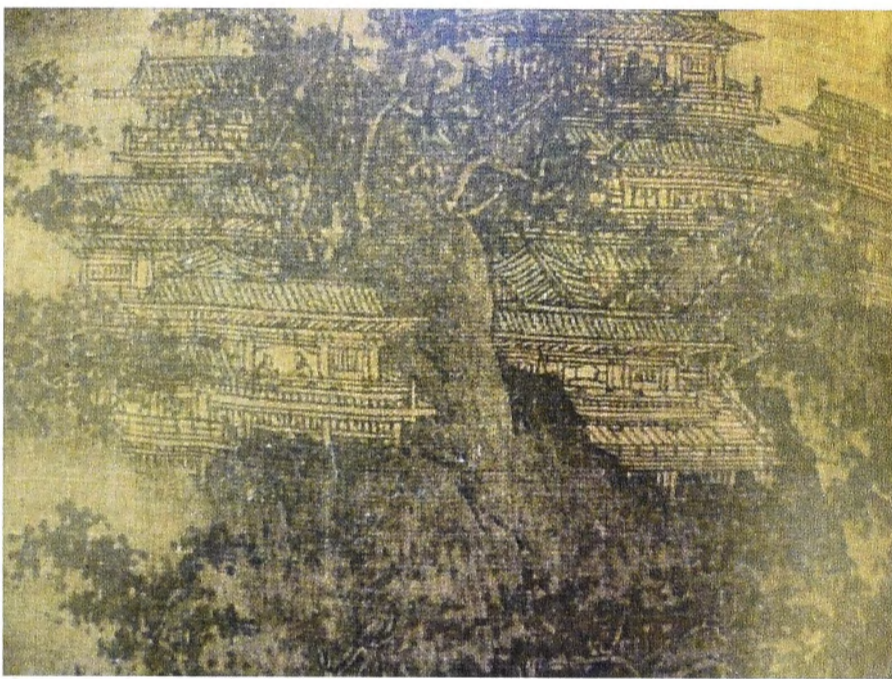
³³ Hearn, *How To Read Chinese Paintings*, p. 20.

³⁴ *Ibid.*, p. 23.



(Figure 3)³⁵

Continuing left, we encounter more travellers on foot who seem to be in a hurry to get home or join those at the tea-house located below the temple perched on the rocky outcrop (Figure 4).



(Figure 4)³⁶

Finally, as we “walk” towards the end of the painting we are met with another figure crossing a footbridge – the only moving human figure that is heading in the direction that the rest of the travellers are coming from (Figure 5). This tells the viewer to “return” their focus to what they just traversed and contemplate the landscape as a whole.

³⁵ *Ibid.*, p. 22.

³⁶ *Ibid.*, p. 24.



(Figure 5)³⁷

The way the individual elements are arranged into a coherent composition in “Summer Mountains” demonstrates a unique graphical perspective that is not quite the same as what is typically presented in Western visual art. A realistic image can be re-produced as if being seen through the viewfinder of a camera via the effect of lights/shadows and the use of colour. The size of the object’s dimension is also approximately represented on the flat surface as it is seen by the eye. However, I find that the graphical, linear perspective so important in Western art is rendered questionable by Chinese landscape painting’s non-realist representation. For example, the aforementioned scroll paintings of natural landscapes do not necessarily reflect the reality of what certain areas in China look like. In fact, “Summer Mountains” is an imaginary landscape conceived by painter, Qu Ding. Moreover, the mountains are made immense by virtue of the smaller foothills and outcrops and humans are disproportionately small by virtue of the vastness of nature. The painter is concerned with the expression of the inner spirit without the distractions of technique, style, and the use of colour, light, or shadow. Nor do these landscapes mimic nature. Appreciating Chinese landscape painting does not mean appreciating what is visible or the pastoral ideal that is sometimes embedded in Western landscape painting. Rather, it means to take in all of the elements in the composition as the painting is

³⁷ *Ibid.*, p. 26.

being un-rolled to participate in the journey and be spiritually absorbed by the whole once we reach the end of the scroll. The human landscape, when interpreted as a whole picture, is also anti-perspectival in its appreciation.

The Heart (心, Xin)

The mind-body dichotomy that characterises the concept of Western medical science has placed the heart (and all matters of the heart) as the binary opposite of the brain. Whereas the brain is rational and sensible, the heart, as an internal organ, is imagined as a pump in the body-as-machine metaphor. In the English-speaking world, the heart is also considered the seat of all feelings and emotions (e.g., we say we should “follow our hearts” when caught in a dilemma between what we think we should do and what we *want* to do). In contrast, according to the theories of TCM, the brain does not even belong to the Zang-Fu system. Instead, it is the Heart that is “the monarch of the human body”, as Men and Guo explain:

The superior form of spiritual activity, according to the ancient Chinese, is thinking governed by the heart, the monarch of the human body. A vivid case in point is the written form of the Chinese character “thinking”, with “heart” as its residence. The heart generates feelings by sensory contact with the outside world, and thus produces the perception and cognition of outside substances.³⁸

As a result, the heart is the palace that houses the union of the mind and body. This offers a new perspective on our emotional changes and somatic dysfunctions. Previously regarded as not necessarily related or corresponding to each other by biomedicine, TCM provides a perception in which symptoms, sensations, and feelings are correlated, as Thomas Ots writes:

Thus specific emotional changes and specific somatic dysfunctions are viewed as corresponding with each other and often as identical. The difference between the Western and the Chinese view is not that of a

³⁸ Men and Guo, *A General Introduction to Traditional Chinese Medicine*, p. 10.

dichotomised Western and a supposedly holistic Chinese view of body-mind. The difference lies in the Chinese assessment of an emotional body.³⁹

An “emotional body” describes how psychological and somatic symptoms are linked and embedded in the TCM semantic network, which is further illustrated in Ots’ own experience of vertigo. According to Ots, vertigo is the most frequently cited complaint among Chinese patients worldwide. During his fieldwork in China, Ots suffered from nausea after eating a lot of snacks that did not mix well and he was sure that he had strained his stomach. Meanwhile, the Chinese friend travelling with him was also eating the same snacks and complained of vertigo instead of nausea. It was not until sometime later that the friend remarked that he also felt something was wrong with his stomach. Ots also tried “to experience vertigo, and actually found that this was not very difficult, because the nausea was associated with a feeling of unclarity or confusion in my [Ots’] head”. This experience convinced Ots that while Western medicine had taught him to instinctively locate the cause of his nausea in the stomach, his Chinese friend “cared less for the cause and for the locus of attack but sensed a bodily imbalance and was engaged in evaluating its seriousness”.⁴⁰

In the view of biomedicine, vertigo can be caused by a range of factors, from high/low blood pressure and heart disease to other psychiatric triggers such as anxiety and panic attacks. However, because the interaction between the psyche and soma is taken as clinically significant in TCM, the coupling of physical symptoms and their corresponding mental states is a sign of the meaningful manifestation of a disharmony in the human landscape. Anxiety and heart palpitations, fear and swelling, and revulsion and nausea are not just psychosomatic – a term implying a linear, causal relation in one direction or the other, usually from the mind to the body. Instead, they are the simultaneous emotional and physical expression of the whole

³⁹ Thomas Ots, “The Angry Liver, the Anxious Heart and the Melancholy Spleen: The Phenomenology of Perceptions in Chinese Culture,” *Culture, Medicine and Psychiatry* (Vol. 14, No. 1, 1990) p. 26.

⁴⁰ *Ibid.*, p. 39.

being with a concomitant single *Yin-Yang* manifestation, such that emotional and physical changes correspond with each other. Whenever one side is upset, the *Yin-Yang* balance tips and the harmony of the whole picture is disrupted as a result. Vertigo can thus be treated as a physical/psychological manifestation of a sensed imbalance. Thus, one can understand Vertigo not necessarily as a disease (with symptoms such as dizziness), but as a sign of how the mind and body as a whole is affected by a sense of disharmony. The whirling and spinning sensation makes it difficult for a person to stand or walk, and such dizziness thus requires the person to lie down – to rest and regain balance. The fact that one's feelings cannot be separated from one's bodily functions is fundamental in understanding TCM because the human landscape is meant to be an integration of the whole governed by the Heart. In the case of vertigo: "It is interpreted as a symptom of enraged anger (liver) or as an expression of anxiety (heart)."⁴¹ The emotions in these "emotional organs" are metaphorically used to indicate a physical dysfunction/imbalance, but that does not necessarily mean that there is a direct biological cause to this sensation. In fact, TCM, like many other alternative medicines, is often characterised by a blurred distinctions between the mind and body. Using the term "subtle body" to describe a particular model of the body in which "subjectivity is understood to be comprised of matter-consciousness" in the form of an energy, Johnston and Barcan conceptualise the energy as constituting the mind and the body, and consequently, "changes in this energy (in this subtle body) at any level – mentally, physically, emotionally, spiritually – will bring about changes to all other aspects of the individual".⁴² As such, we can say that Ots' example of the emotional body is just one "sheath" of what comprises the body. When the stomach is reacting to the food that is not settling well,

⁴¹ *Ibid.*

⁴² Jay Johnston and Ruth Barcan, "Subtle Transformations: Imagining the Body in Alternative Health Practices," *International Journal of Cultural Studies* (Vol. 9, No. 1, 2006), p. 30.

the subtle energy (*Qi*) is affecting beyond the flesh. However, particular to TCM, it is the heart that joins both the internal and the external; or the physical and the mental/emotional; personal and the social.

As the monarch of the human landscape, not only does Heart sit commandingly like a mountain at its centre, but also it rules life. This is best illustrated by the use of the word “heart” within the Chinese language. The character heart (心) can be used along with one’s emotions (as in 心情, literally meaning “heart sentiment”), or thoughts and cognitive processes (as in 心思, the second character is written with the radical “field” on top of the “heart”, which indicates that thinking is also the function, or field, of the heart). The heart can also be imagined as a foundation, and the term 心地 (translated as “Heart Foundation”) is used to express one’s character and personality. For example, if someone is known to have a “good Heart Foundation”, it means that they are kind, willing to help others, and moral. Similarly, if someone has a “bad Heart Foundation”, it means that they are vengeful, mean, and untrustworthy. Therefore, the heart is an all-embracing expression of human concerns – be they ethical, social, or personal. I say personal because the person to whom the “heart” belongs is responsible for its quality.

Moreover, the Heart can also be found in the understanding of one’s illness. According to TCM, all illnesses can be traced to one or more of the following three causes: internal, external, and neutral. Internal refers to our seven emotions: joy 喜, anger 怒, worry 忧, 思 (this versatile character can mean “to remember”; “to mourn”, as in the word “homesickness” 思乡, which is literally translated as “remembering hometown”; or to think or contemplate, as in 思想), sadness 悲, fear 恐, and shock 惊. It should be noted that with the exception of joy, the rest of these emotions, when

written in Chinese, have the radical “heart” (心) beneath or its variation (忄) on the left. This shows that not only do the Chinese use the Heart to feel emotions and think as previously mentioned, but also to mourn and grieve, which often results in a “Heart Ache” (心痛) that requires more than a few wise, comforting quotes or friends’ advice to heal. Externally, illnesses can be caused by “pernicious influences” such as dampness, wind, cold, dry, heat, and fire. Each of these influences is believed to resonate with and most easily affect a corresponding organ. For example, dampness most easily affects the Spleen while wind affects the Liver. These are based on the understanding that the human internal processes actually mimic and resonate with external climatic conditions.

Finally, within the human landscape, the heart also forms its own “Landscape” (心境). In some circumstances, this term can be translated as the English equivalent of “mood”, but it is actually more than just the description of the present state of how one feels. The “Heart Landscape” is the description of the “state of the Heart” resulting from years of experiences and changes/adaptations. Unlike the Heart Foundation, the Heart Landscape is strictly personal and private. For example, whether one has a calm or disturbed Heart Landscape does not make her a better or worse person in other people’s eyes. However, most Chinese speakers would probably agree that if one’s Heart Landscape is calm, one is less susceptible to diseases such as cancer and mental illness.⁴³ Therefore, people who are more prone to spiritual satisfaction will have a calm Landscape, whereas a disturbed Landscape makes the person more prone to stress-induced illnesses. The Heart Landscape is thus one of the common body-related verbal expressions that transcend the dichotomy

⁴³ The belief that stress causes cancer is not shared by oncologists and Siddhartha Mukherjee claims that “A positive attitude does not cure cancer, any more than a negative one causes it” (see Decca Aitkenhead, “Siddhartha Mukherjee: ‘A positive attitude does not cure cancer, any more than a negative one causes it.’” *Guardian.co.uk*, 4 December 2011).

of one's psyche and soma. Like those miniature and private gardens that serve to cultivate the mind and spirit by appreciating nature in its various forms, the Heart Landscape is an element within the human landscape that can be arranged and organised. By aligning the Heart with the natural landscape, the Taoist ideal can finally be upheld, such that "by taking nature as a model, human beings seek in effect to become once again a part of nature and to experience spiritual oneness with it".⁴⁴

Healing Landscapes

Because *Yin-Yang* is the only theory used to explain the workings of the universe, including those of the human body, TCM is often regarded as elusive and "unscientific". However, this should not be used to dismiss TCM as "superstitious" or "incomprehensive". Rather, it is precisely this characterisation that allows it to be creative in its healing practice. For example, it should not be surprising to learn that no two TCM practitioners will prescribe the same treatment for the same illness, even for the same person. The herbs dispensed by the pharmacist are not meticulously weighed out and the standardised uses of herbs are not always pivotal in herbal medicine. The use of uncommon herbs, unusual quantities, or even unexpected combinations can become a practitioner's signature style that he uses to distinguish himself from his competitors/practitioners.⁴⁵ The general lack of standard definition regarding the states of health and illness in a person further reinforces the popular belief that TCM is "elusive". Take the signature practice of pulse-taking in TCM, for example. It does not just measure one's heart rate, but also how the pulse feels to the touch of the practitioner. Two people can have different pulse-rates and pulse patterns and still be equally healthy. The same goes for tongue examinations – a tongue can appear red and dry or pale and damp, but neither of these visual signs

⁴⁴ Shaw, "Buddhist and Taoist Influences on Chinese Landscape Painting," pp. 185-6.

⁴⁵ Zhan, *Other-Worldly*, p. 70.

alone indicates whether an individual is healthy or ill. However, it is precisely because of both the elusiveness of TCM and its resistance to considering the human body as a machine that offer us a different perception of health and illness. It is also a way out of the deadlock created by the linear and reductionist thinking that is typically associated with biomedicine and its discourse.

When we visit a biomedical doctor at a clinic, our physical problem is often re-described in biomedical language and the cause is explained biologically. For instance, a sty in the eye is caused by the obstructed orifices of the oil glands in the eyelid and diarrhoea is caused by a bacterial infection, whereas our everyday experiences such as stress from work or sensitivity to the environment are typically dismissed as inconsequential to the diagnosis.⁴⁶ If a person is suffering from diarrhoea and a sty at the same time, they may well be considered two unrelated problems. After all, one has to do with the glands around the eyelid and the other involves the gastro-intestinal system and its function. These organs are not related to each other functionally or biologically. In TCM, these two problems may also be regarded as two separate issues, although for another reason, as Judith Farquhar explains:

[TCM] links manifestations of illness to causal narratives not with reference to an underlying anatomical field but in relation to temporal emergence. The appearance of symptoms in sequence or at the same time suggests that they are related phenomena, and the physician's job is to identify the process that could produce symptoms in precisely this temporal relation.⁴⁷

Although common sense seems to separate them, a sty and diarrhoea are not necessarily unrelated symptoms. Their relation actually depends on what has happened to the patient as a whole within a certain time frame.

⁴⁶ In some cases, diarrhoea is the result of non-acclimatisation to a new environment and in TCM, it is believed that this happens when food cannot be digested well, resulting in stagnation in the abdominal area. Stagnation causes heat, which upsets the body's internal environment.

⁴⁷ Judith Farquhar, *Appetites: Food and Sex in Postsocialist China* (Durham and London: Duke University, 2002) p. 64.

Such dependence on individual circumstances also suggests that “temporal emergence” is important in framing and contextualising the healing landscape of TCM. Because it is not the practitioner’s job to generalise the patient’s narrative/account into a single sign of illness, the patient is always free to connect her ailment to her expansive daily experience. The purpose of a clinical encounter is to search for the intervention of a problem “articulated to the many facets of the complaint itself”.⁴⁸ This is achieved through the joint efforts of the patient’s input and the practitioner’s skilled interpretation, with the patient regarded as the “artist” offering a painting of his body’s landscape for the practitioner to view to identify its composition, harmony, and disharmony. Both parties are trying to discern a healing landscape within this “painting”. Likewise, the need for a multifaceted narrative means that the healing landscape in TCM is more than a picture to be interpreted simply by looking. The added temporal dimension lends the healing landscape a textured surface for both the patient and the practitioner to “walk on”. As such, we are more likely to discover new types of causality in the various encounters and experiences along the way. These new causalities are made possible by two conditions. The first is communal. Most TCM clinics in China do not have a private consultation room (in fact, it is not so common in the West, but can be easily found in China). Patients waiting to be examined are also participants in the conversation between the practitioner and the patient sitting across from him. They are free to throw in their opinions or share their experiences. As such, the one-way communication of a typical clinical encounter gives way to a non-hierarchical version. Through this communally-formed network, the patient can actually come up with a new perception of his own experience that he might have previously overlooked. The

⁴⁸ *Ibid.*, p. 71.

second, and perhaps more important of the two conditions, is the ability to involve other sensations that relate to an illness.

Consider the sense of taste as an example. Within the semantic network of TCM, the sensations of Sweet, Sour, Bitter, and Pungent have medicinal power. Citing a 1978 pharmacy textbook, Farquhar notes that Pungent spreads and disseminates to move *Qi* or blood and nourish with moisture. Sweet replenishes and supplements to regulate the activity in the Triple Burner and moderate acuteness.⁴⁹ Not surprisingly, one's life experience can also be described in flavours. For instance, a "sweet" life can mean a life of happiness while a "bitter" one suggests a lifetime of hardships and a lack of the opportunities needed to escape adverse situations. A "sour" life can mean a life of misery, perhaps aggravated by envy, jealousy, or an irreparable mistake, whereas a "pungent" life can mean that an individual has faced a lot of exciting challenges in her life and taken many risks. Just as psychological and physical responses are mutually corresponding and simultaneous flavours can equally elicit a sensed response from the body. Because food is classified into *Yin* and *Yang* and the aforementioned five flavours "in ways that are well known to many who have never studied medicine",⁵⁰ even homemade Chinese medicinal meals are usually prepared in accordance with the efficacies of food and what one has recently experienced. For instance, after a particularly hard day, most would agree that a bit of sweet alleviates sadness/stress. In medicinal meals, a winter cough is due to dryness and heat in the Lungs, so almonds are eaten to relieve the symptoms by replenishing the lungs with a bitter-sweet flavour combination. Likewise, eating spicy food can actually help the circulation of bodily fluids and blood when one feels sluggish.

⁴⁹ Chengdu College of TCM, 1978: 7, cited in Farquhar, p. 65.

⁵⁰ Farquhar, *Appetite*, p. 70.

Because this is not a study of the philosophy and theories of TCM, how flavours are categorised in relation to food and their efficacies are too technical to be included in this chapter, but I must emphasise that each herb, like food, has its own flavour classification and their use/combination is never standardised. These examples are sufficient to show that each patient is treated as a unique medical case based on her own personal story and experience, which may then appeal to her use of different sensations to describe the illness that is not limited to the description in biomedical language. Diagnoses and prescriptions vary from patient to patient, not symptom to symptom. In this way, holism in TCM does not refer to the biological causes within the anatomical space. It creates a non-linear, iterative, and reciprocal healing experience of its own that resembles the un-rolling of a (human) landscape painting.

Behind the Landscape

Finally, I argue that the healing landscape of TCM cannot be singled out and placed within a self-enclosed system (such as the biomedical system or the Chinese thinking system alone). In fact, it must be juxtaposed with what biomedicine can and cannot do if it is to be recognised as a “different” science. The healing landscape in *Avatar*’s Pandora is not just painted in bioluminescence, it is illuminated by its antagonism; that is, by the over-populated and corrupt, post-industrial society represented by the nature-destroying, exploitative humans. In the same vein, TCM’s healing landscape needs its antagonist to “appear” just as “magical”. TCM is founded on a myth and represented by the mythical figure, Shen Nong – believed to have lived over five thousand years ago – known also as the founder of Chinese agriculture and herbal medicine. It is believed that he was born with a transparent body with the exception of his head and four limbs, and that his internal organs would turn black if

he was poisoned, which made it easy for Shen Nong to test and identify which herbs could poison which parts of the body.⁵¹ It has also been documented that he tasted one hundred herbs and ingested over seventy types of poison in one day, eventually dying of food poisoning. Given such an origin, with borders more chimerical than allegorical, it is not uncommon for Chinese people to think of TCM as a cult religion. For example, if a friend is suffering from a chronic/serious health problem that cannot be cured or improved by biomedicine, a Chinese person might suggest other alternative options. He might ask, “Do you believe in TCM?” and then go on to recommend a particular *Yi-Shi* (i.e. Chinese medicine practitioner)⁵² that “miraculously” cured a friend or a friend of a friend/relative. Clearly, the question first addresses TCM’s questionable status as a legitimate medical system (one does not have to “believe” in science), and the list of “miracle” cases that follow places TCM firmly in the better-than-science realm. It is as if TCM, even within the Chinese context, is so far away and ungraspable that it would require faith to sustain. However, as I mentioned at the beginning of this chapter, despite its mythical origin and its ambiguous status in most people’s minds, TCM is gaining popularity and acceptance both in the West and the East. It is now quite common to find testimonies on the Internet from people claiming that alternative treatments such as TCM saved their lives, or how a single acupunctural session significantly shrank a tumour. Many self-help books have been written to confirm these “miracles”, but what exactly is TCM in the world of biomedicine?

Present-day TCM no longer refers exclusively to medicine as practised in China, or practised by a Chinese practitioner. It is also not the only place Chinese

⁵¹ Lihui Yang and Deming An, *Handbook of Chinese Mythology* (California: ABC-CLIO, Inc, 2005), p. 191.

⁵² The term *Yi Shi* (醫師) is used in the Chinese language to differentiate Chinese Medicine practitioners from biomedical doctors.

people turn for treatment. In fact, when comparing the attitudes of people in Hong Kong towards Western and TCM, T.P. Lam remarks that given that both types of medicine are used concurrently by many people in the territory, patients “make decisions on which type of doctors they want to see for the specific illnesses that they are suffering from”.⁵³ According to Lam’s study, most people consider TCM to be better for curing the root of the problem, but is slow in action. Although it is also common to believe that Western medicine is better at controlling symptoms, it is TCM that can “clear the root of the disease” or “cut the tail of the illness”.⁵⁴ Thus, it is mostly used by people in Hong Kong “as a supplement to Western medication”. This confirms that it is its otherness that gives it its credibility.

According to her fieldwork on the translocalisation and globalisation of TCM in Shanghai and the San Francisco Bay area that spanned a period from 1995 to 2005, ethnographer Mei Zhan argues that it is precisely the marginalisation and the *othering* of TCM by the scientific, biomedical mainstream that transforms and constructs its clinical efficacy as “miracles”. TCM has become known for producing something out of the ordinary.⁵⁵ Using an example from her case study, Zhan explains how it is actually “by coincidence” that herbalist Pang Panchi became a famous cancer specialist in Shanghai, China after all of her biomedical colleagues had declared a patient’s case of ovarian cancer to be “hopeless”. Interestingly, it was not until all hopes were exhausted that the patient’s mother begged Pang to take on her daughter’s case. Pang then diagnosed the patient with “*Yin* depletion” and kidney deficiency. However, after taking Pang’s initial prescription, the patient did not become better.

⁵³ T. P. Lam, “Strengths and Weaknesses of Traditional TCM and Western Medicine in the Eyes of some Hong Kong Chinese,” *Journal of Epidemiol Community Health* (Vol. 55, No. 10, 2001), p. 763.

⁵⁴ *Ibid.*, p. 763.

⁵⁵ Zhan, *Other-Worldly*, p. 93.

Pang subsequently decided to turn to another, more senior *Yi-Shi* for help, as Pang recounts:

He suggested a ready-made prescription in the Tang Dynasty medicine book Qianjin Fang. I changed a few herbs in the prescription and gave it to the patient. In a month, all her symptoms disappeared! She then went to the Women's Hospital in Shanghai to get a lab test. The report came out negative, and her tumour was gone! The news went around, and all sorts of cancer patients started to see me, hoping for miracles like this.⁵⁶

Zhan notes that it is the fact that this particular patient's case was "leftover" – had been deemed hopeless by biomedicine – that defines Pang's clinical success. Nonetheless, Zhan is quick to add that while it is being translated as a "miracle", the mechanisms of Pang's treatment are never explained, which shows that when TCM interacts with biomedicine, TCM does not and cannot stand on its own merits. In *We Have Never Been Modern*, Bruno Latour describes the two Great Divides that separate Nature and Culture and Us (the West) and Them (all the *others*). While Westerners can separate nature and culture, they also see that *others* have conflated nature with culture.⁵⁷ Thus, the West only *becomes* the normative conceptual space for science and biomedicine due to its self-induced separation from nature. Meanwhile, TCM becomes the non-Western "alternative" because of its non-dualistic way of viewing nature-culture. Coincidentally, these numerous instances of "miracle-making" also allow Zhan to argue that the Great Divides are constantly being pushed and dismantled, which forces us to keep redefining what counts as science and challenging what we assume to be the "predictable" logical reasoning that makes sense of the natural world. This is particularly true in the realm of health and disease where science is the only system available to frame our understanding. Although we may also wonder how changing a few herbs in a prescription could make a tumour disappear, we must also bear in mind that part of our curiosity actually comes from

⁵⁶ *Ibid.*, p. 108.

⁵⁷ Bruno Latour, *We Have Never Been Modern*. Trans. Catherine Porter. (Massachusetts, Harvard University Press, 1993), p. 99.

our own reductionist and linear way of thinking, which is shaped by the Western scientific discourse that creates the science/nature dichotomy in the first place. The unstated part of this question would be: why is it that when drugs (signifying human victory over the adverse course of nature) cannot cure cancer, herbs (a metonym for nature) succeed? Is it just random luck? To put it another way, the juxtaposition of Pang's unorthodox treatment with biomedicine's conceptual framework and interventionist technology confirms Pang's accomplishment while keeping the significance of her "miracle" (and what TCM can do) ambiguous. As Zhan explains: "[Pang] has accomplished what biomedicine cannot, and yet the rationality of her success is not accounted for."⁵⁸ This also begs the paradoxical question of how to explain and theorise "miracles" (or the unpredictable) using only the discourse of science.

Granted, Pang's curing of her patient can only be made meaningful in hindsight. If successful, it is either a "clinical miracle", or a "coincidence", as Pang herself calls it. Alternatively, it can be shrugged off as a "reasonable expectation" if it turns out to be a failure. Miracles are miracles (or "happy chance" or "coincidence") only after the fact. It is the same way in which we understand any kind of accident. For example, a sober driver driving within the speed limit and arriving at her destination safely is considered part of a natural course of events. No causality is needed to explain it. However, if a driver driving at the same speed crashes into another car in the opposite lane, it becomes an accident with blame attributed to one or both drivers. Like miracles, which are usually only defined as such in response to a favourable turn of events, an accident – something unplanned, undesirable, and unfortunate – becomes what it is after the fact. When something unplanned goes unexpectedly, even extraordinarily well, it is a miracle. Accidents and miracles are

⁵⁸ Zhan, *Other-Worldly*, p. 109.

therefore two sides of the same coin and the unique thing about both accidents and miracles is that they keep on happening, but no two instances are the same. This is because neither accident nor miracle can be manipulated.

Here is another example. The sentence “The Exquisite Corpse will drink the young wine” does not make any semantic sense, despite the fact that the sentence follows a faultless (syntactic) sentence structure. This is just like our driving example, in which nothing is wrong with the drivers, the traffic, or the mechanisms of the cars. The abovementioned sentence bothers us, nonetheless, and we can only attribute our irritation to the meaningless, random selection of subject, object, adjective, and verb. However, the same sentence will immediately make sense to us if we learn that it is the result of a popular parlour game in which players have to write a phrase on a sheet of paper. The paper is then folded to conceal part of what has been written, and it is then passed on to the next player for his contribution.⁵⁹ The game, which has its origin in surrealism, is an exploitation of the concept of an accident that creates a collective collage of words on a blind, unfolding, networked surface. Through each player’s giving, taking and interacting, what was “severed” and “discontinued” is brought back into one piece again – although it is sutured, piece by piece, with each piece leading to a new direction that cannot be foreseen. According to Michael Joyce, within the system of “folding and concealing”, which is followed by extending, preserving, and disclosing, even “irrelevant criteria” that are normally outside of our common sense and understanding can become part of the collage of such collaboration.⁶⁰

⁵⁹ Source: <http://www.exquisitecorpse.com/definition/About.html> (Last accessed 15 December 2011).

⁶⁰ Michael Joyce, “‘Together in Their Disharmony’: Internet Collaboration and Le Cadavre Exquis,” *The Exquisite Corpse: Chance and Collaboration in Surrealism’s Parlour Game*. Ed. K. Kochar-Lindgren, D. Schneiderman, and T. Denlinger. (Nebraska: University of Nebraska Press, 2009), pp. 164-188.

Returning to the driving example, following an accident, we begin to break down the act of driving into other “irrelevant criteria” that have nothing to do with the “technique” of driving. These criteria include the mental/physical state of the driver, what she has eaten prior to driving, the condition of the car, the traffic, the road condition, the weather, and even the mental/physical state of the other drivers sharing the road. This is also reminiscent of the Actor-network Theory in which both humans and non-humans are enlisted in networks to become allies through interactive links. In this case, it is only when a sentence about the “exquisite corpse” turns up that we begin to notice the sutures concealed behind the networked surface. When a disease like cancer can no longer be understood simply as the invasion of an external agent, it is time for us to imagine healing as also situated in a complex system of networked surfaces. According to Paul E. Plsek and Trisha Greenhalgh: “a complex adaptive system is a collection of individual agents with freedom to act in ways that are not always totally predictable, and whose actions are interconnected so that one agent’s actions change the context for other agents.”⁶¹ The human body, which has always been known as a self-regulating physiological system, can now be multiple and interacting bodies within an inherently complex biological and social system. Our past experiences and our unique and adaptive responses to new stimuli from the environment now also get to determine what we are made of and how we will behave. The web of relationships we form alters our beliefs, expectations, and behaviour, such that these relationships are embedded within the wider social, political, and cultural systems. Sometimes the web is formed all at once and seamlessly, but more often it is formed via the relationships that take place one after another like the process of folding and suturing before being passed on to the next hand. Because each agent in each system is simultaneously nested within other systems, it becomes impossible

⁶¹ Paul E. Plsek and Trisha Greenhalgh, “The Challenge of Complexity in Health Care,” *British Medical Journal* (Vol. 323, No. 7313, 2001) p. 625.

(and unnecessary) to understand each agent and system as an individual entity. All of these systems and the agents within them can equally influence or even produce outcomes in entirely novel and unpredictable manners.⁶²

When cancer is among the many diseases that cannot be fully explained by biomedicine, it drives cancer patients to seek answers elsewhere, but what they are searching for is actually a different mode of causal relationship that opens doors of hope that are not found in conventional biomedical science. These hopes, in turn, do not necessarily hinge on finding a complete cure. They are more about having the ability and confidence to expect the surprises that one may encounter if one dares to take a different turn. Hence, TCM does not need to be cut off from everything around it to establish itself as its own science, nor does it need to be an imaginary *elsewhere* to justify what it can do. It is, itself, the “elsewhere” that is within everything else. Only when we place TCM in a more complex system beyond the boundary of Western science and biomedicine can we see that the healing can be aleatory, open to chance, and circumstantial. What we have chosen to call a “miracle” might be the abbreviation of a more complex and ultimately less palatable reality – one that includes failures, accidents, and sheer luck in the matters of our lives and deaths.

⁶² Tim Wilson and Tim Holt, “Complexity Science: Complexity and Clinical Care,” *British Medical Journal* (Vol. 323, No. 7313, 2001) p. 685.

Conclusion

The aim of this project has been to understand cancer and its experience from a spatial perspective. I have argued that rather than understanding cancer as a disease characterised by a linear illness trajectory, a spatial story of cancer can be an added dimension that enables us to pay attention to what is around us and around the illness. This act of looking *around* (instead of just looking *ahead* and looking *back*), in turn, enables us to associate with and relate to what is around us more freely. As a result, the spatial perspective offers us a different perception of the cancer experience, giving rise to nuances in the stories of cancer that are more than what the previous temporal model can plot.

In order to locate what is *not* in the main narrative, the first three chapters of this thesis discussed the “unspeakable” part of the cancer experience. Not only is there a lot more to what the discourse of science and biomedicine cannot explain about the disease, there are other knowledges that cannot be fully grasped in its scientific representation. Unsurprisingly, when there are other knowledges that cannot be described by the scientific narrative, they are conveniently treated as non-scientific, controversial, and hence, untrue. What cannot be represented by science is sometimes told through the patient in the form of a personal cancer narrative. But even these personal accounts have their own silences, especially when they involve fear, pain, loss, dying and death. They are silenced because most of the time they are beyond the access of language. However, as I have shown, this silence by no means warps the cancer experience. Quite on the contrary, these silenced stories form what I called a negative presence – it is there even though it is not visible, and hence it can only be through looking at what is *around* that we realise its presence. And it is from what is invisible and yet present that we can catch a glimpse of the more divisive

realities that also constitute the (collective) story of cancer. These silenced stories, whether they are in the form of a ghostly presence, or in the form of an ellipsis, or are only expressed via the telling of (vulgar) jokes, tell us there is never a proper way to tell a story of cancer in one language, one voice, or one genre.

Spatialising the story of cancer offers us an opportunity to situate cancer in the very same space with us, and to experience the illness in its various forms and shapes. This can be rather different to simply looking at the illness experience as a series of events on the two-dimensional timeline. As Chapter Four showed, even though Helen Garner's novel has depicted healing as sentimental, and at times even emotionally and physically painful for both Nicola and Helen, it has enlightened us with the *othered* realities of cancer that can only be lived and witnessed by the *others* – namely, the objects in the spare room. In addition, within this space, the fuzzy line between dying and hoping is constantly drawn and redrawn. In Chapter Five, Maggie's Centre exemplified how our illness experience can interact with the spatial experience, giving rise to a spatial topology that characterises the architecture of healing. And it is precisely via interacting with the immateriality (of other people's stories of cancer) and the materiality of the architecture that different layers of cancer reality emerge.

Finally, I argued that a spatial story of cancer allows us to take an imaginary first step onto a journey of healing. Chapter Six showed how a healing journey enables us to rise above a despairing situation and to move around and look for an exit out of the space of cancer. It allows us to visualise hope. I then used Chinese medicine in Chapter Seven as an example of an alternative path to healing. Without having to link any disease to one single pathogen or a gene, the natural environment and the human body are thus no longer necessarily understood in dichotomous terms.

As a result, Chinese medicine is one of the alternative paths that frees the notion of healing from the boundary of biology and anatomy, and allows us to take on an “anti-perspectival” view on health, illness, and the human body. In short, spatialising the story of cancer, or having the story of cancer told through space, ultimately led us to approach healing as a way to make sense not just of our body and our illness, but also our body’s *relation* with the illness, as well as the illness’s *relation* with the environment and the society.

Implications of Findings

This project has opened up other realities that are emerging from stories of cancer, and in particular, it emphasises the fact that death and dying is just as legitimately a part of the cancer experience as surviving. In contemporary societies, cancer has been portrayed as a disease in which one has to be brave in order to survive.¹ To be brave means one has to stay positive and be open to different treatments necessary to kill the cancerous cells. That is, one is expected to *fight* cancer. Being brave can also mean one is vocal about what having cancer is like, is keen to take part in its politics, or is critical and sceptical about the so-called scientific figures and statistics (such as survival rate) that try to predict one’s future in the most authoritative way. To be brave is an attitude promoted by our culture as a means of taking matters in our own hands. Being able to find new meanings and enrichment in life despite our affliction, to look cancer in the eyes and dare to face it down at all costs are all worthy of applause. However, the diversity of expression, the richness of response are inevitably lost amongst all the heroic tales of survival that are all too ready to convince us cancer is just another disease that needs to be treated. In reality, cancer is a threat that continues to haunt the patient. To focus solely on survival and

¹ See Lisa Diedrich, “A Bioethics of Failure,” *Ethics of the Body: Postconventional Challenges*, ed. Margrit Shildrick and Roxanne Mykituk (Cambridge, Mass: MIT Press, 2005), pp. 135-152.

neglect the healing/dying pain can be just as nullifying as silence itself. Thus, one advantage of having a spatial perspective in addition to a temporal one is that it captures not just silence but also the trails and traces left behind by time, spawning more diverse stories of cancer, through which more nuances and even ambiguities can be recognized.

Also, this thesis emphasises the fact that cancer is simultaneously about the life/lives surrounding around it. And since it is not contagious, and having a tumour growing in the patient's body does not necessarily affect the wellbeing of the others around him, cancer used to be imagined as being confined within the ill body of the patient alone. Yet, with better medical treatment that results in the patient having a better chance at surviving his initial diagnosis, cancer is becoming a "family disease." What this means is that cancer is no longer just a personal physical affliction, but it involves the decisions that have to be made by the patient and his/her family as a unit. These decisions may include what kind of treatment is most suitable for the patient, how to make the best arrangement to care for the sick, or whether or not to seek second opinions. Family plays an important role in one's cancer experience, and for this reason, I find it crucial to include their role in shaping the story of cancer, especially in the journey of healing. For example, *Exploding Into Life* and *2 Become 1* are not just about the patient's suffering of her cancer only. The former, being a collaborative work, Eugene Richards becomes a witness (using his camera to document the witnessing) to Dorothea Lynch's breast cancer. He also plays an important role in telling his readers about how her cancer has afflicted him. The latter tells the story of breast cancer as more than just a physical ailment; rather, it is at once about the protagonist's (Bingo's) sex life, the problems she has to face at work (before and after cancer), the feelings of hurt when betrayed by an ex-partner, and the possibility of falling in love again. Thus, instead of being a medical problem, in

which both the physician and the patient are regarded as “heroes” if the patient survives, these two texts are examples, among many others, that showed what kind of story it can become when cancer is also located in our everyday life, and in particular, one’s family life.

Instead of understanding healing as a process of freeing ourselves from pain and suffering, I have redefined healing as located right within the illness experience itself. Healing thus takes place around the patient as a kind of movement, forming a space of healing. To put it differently, if space allows movements, then movements also allow us to visualise how healing can “travel” or come to us in different form and shape; materiality and immateriality, such as a massaging hand, a soothing tune, a room of a friend’s house, or a community centre. Healing, in other words, is not static, nor is it something that takes place between an agent and the patient only. It is more like an constant negotiation and interaction between objects and humans, requiring participation on both sides. To take this even further, what this space of cancer also means is that since the temporal representation of pain can only let us know about other people’s pain from a distance, resulting in pain remaining unknowable and deeply personal, a spatial representation, I hope, can open ourselves to a new sense of relational proximity through imaginations. As such, within this proximity, the pain from shattered hips from a car accident, or from the loss of a child, or from a cancer surgery, or from broken ribs caused by an abusive partner, can all be related. Once pain is freed from time’s causal reasoning and judgment, it becomes a collective experience – not just about the disease alone, but as a conversation with one another through the medium that is spatial, creating a life-sustaining intimacy that is a domain of healing beyond language.

With this new perspective of telling the story of cancer, a more complex vision of the relationship between illness, death and dying is achieved. And it can also encompass hope, despair, bad luck and even miracle, which are all part of what living with cancer means. Indeed, we have never been too comfortable with using the notions of “miracle” or “accident” to account for something good or bad that has happened to us. There is always a reason or a cause to explain almost everything. However, when we hear about how people cure their cancer by the power of prayers, or how by the sheer force of will power a person’s tumour has miraculously shrunk, do we regard them as purely exceptions to the law of nature? Or do we consider them as part of the cancer reality? The spatial perspective of cancer does not offer to explain how miracles or accidents happen, but it offers a new dimension in which we may find it possible to explain an effect with more than just a reductive cause – we may even come up with something that even eludes the grasp of by theory, reason or rationality. By foregrounding the day-to-day interaction with families and friends, health-care providers, and even with the mundane objects and places with which we come into contact everyday, this space is constantly shifting and expanding. And hence, it is open to all kinds of new routes by inviting its inhabitants to be more imaginative and creative about finding their way out of the labyrinthine space of cancer. In other words, not only is it a space where we can have a ghostly encounter, in which we are able to see how a story can be told in such a way that exceeds the temporal boundary of a past, a present and a future, it is also an imaginative space where we can have a brush with a two-headed dragon hiding a precious antidote to our ailment as we take another turn around a corner, conjuring up hope and possibilities along the way.

Limitations and Suggestion for Further Research

Although the spatial perspective can bring about a fuller representation of a cancer experience, I am aware of the fact that much like the temporal perspective, it is just another frame-based representation. And it implies that for everything that is included within the frame, there are just as many things that have to be excluded. Another issue is that the written texts I chose for analysis throughout this thesis are published works only, meaning that they are probably considered as more appealing to the public tastes. However, these few works obviously do not and cannot represent all there is to know about what having cancer is like. Even with the more expansive spatial frame to tell the story, it is still not enough (and it is impossible) to cover every kind of cancer experience. Those who fall outside of this frame may include those who simply cannot tell their stories – young children with cancer, those whose words are too obfuscated by fear, worries or pain, and those whose stories are just not heard at all. And there are also people who do not necessarily have the option or privilege of finding healing through their own community or support networks. Not to mention there are people with cancer who live solitary lives and may have to die alone, too. Without meaning to further silence, marginalise, or make them invisible, I find these wordless stories to be equally essential in portraying the other side of the cancer reality, but it is beyond the scope of this thesis.

This research has been mostly focused on Western representation of cancer and I have limited my analysis of healing spaces and places to the Maggie's Centre network and the Gilda's Clubs that are mainly located in Scotland, Canada and the United States. As such, in my discussion of the process of demedicalisation, I argued that it is through creating an ambience that appeals to our affect that a space can acquire a healing quality, especially for an institutional space like a hospital. Or, in

the example of Maggie's Centre, I showed how a particular architectural artefact is designed specifically for the purpose of conveying a certain symbolic meaning to its users. However, it should be noted that there are certainly other places, spaces, and architecture that are regarded as "healing" in other parts of the world, in which the notion of healing can be interpreted and approached differently according to the different cultural understandings of the term. And there are other kinds of interactions with space through which we are not necessarily required to make sense of its symbolic meanings in order to feel "healed." The Ryōan-ji (temple) in Kyoto, Japan is a good example. Designated as a UNESCO world heritage site, this temple features a garden whose sparse, abstract and seemingly random composition of rocks could intrigue its visitors with its "mysterious" appeal. Constructed in the "dry landscape" called *Karesansui*, the garden is made up of fifteen pieces of rocks arranged into five different clusters. But these rocks are arranged in such a manner that visitors can only see fourteen of them at any time, no matter what angle the garden is viewed from. It is also believed that only when one has attained spiritual enlightenment as a result of Zen meditation can one see the last invisible stone.²

Even though the garden is predominantly made up of empty spaces, to most visitors, it is always a wonder how the placement of rocks, moss and shrubs in a vast garden creates such a mysterious phenomenon. To solve this mystery, one is naturally inclined to look for the symbolic meaning of the rock clusters upon her first entrance. And the rocks can indeed be interpreted symbolically, representing "a tigress crossing the sea with her cubs, or strokes of the Chinese character meaning the 'heart' or 'mind'" from different viewing angle. However, such symbolic interpretations do not necessarily relate to our experience of visually perceiving the

² Source: <http://www.yamasa.org/japan/english/destinations/kyoto/ryoanji.html>

garden as a whole.³ Nor do these symbolic meanings help explain the meaning of the empty space. While it is perhaps in the interest to those in the fields of psychology, or mathematics, or even architecture to explain how empty space can be implicitly structured and arranged so that they can have a psychological impact on our perceptual mechanism, we can also take the Zen concept of emptiness as one of the fundamental non-western concepts of healing. And this may be useful in casting new lights upon what "holism" means. Here, healing does not necessarily mean it is an effort to make one whole, but quite on the contrary, we learn to accept that there is always an incompleteness in our life, and it should be our aim to strike a balance between what we have and what we lack. If we focus on the empty space rather than what the objects (the rocks) symbolise in the garden, the missing piece in the rock cluster will actually alter how the garden looks like as a whole as we walk around it. That is to say, the whole can be considered as constituted by emptiness and/or what is missing, in addition to what is already there.

Finally, I need to point out that even with the growing popularity of traditional Chinese medicine in societies where biomedicine is the dominant medical system, the cultural representation of Chinese medicine is seldom studied. One of the reasons for this is that its merits as a medical practice are often downplayed. For example, Chinese medicine practitioners, when represented in mainstream popular culture, are usually quacks or even villains, but that usually has to do with the character's personality rather than the effectiveness of the medical practice itself. Perhaps one may explain this negative or insignificant portrayal by saying that since biomedicine has already enjoyed having its own language to explain health and illness, its views are always the "truth." The god-like, all-knowing physicians are given a role in

³ Gert J. Van Tonder, et.al, "Perception Psychology: Visual Structure of a Japanese Zen Garden," in *Nature* (Vol 419, Sept 2002).

popular representation as positive, trustworthy, and heroic while all non-biomedical practices have to be rendered as their binary opposite. Or perhaps it is simply because there is nothing dramatic about a pulse examination or inserting an acupunctural needle into a patient, comparing to cutting open a human body with a scalpel. No matter what the reason is, the question as to why traditional Chinese medicine is rarely or negatively represented in mainstream popular culture can only be met with even more questions about how this practice situates itself globally. For example, is science the best way to explain a physical or a social problem? Do people use non-biomedicine only mean a last resort for terminal patients who have not much left to lose? What role does Chinese medicine play in our culture other than being alternative and/or complementary? If it is as Deborah Lupton remarks, "Medicine, or faith in medicine, is a creed,"⁴ then can we have the same faith for other types of medicine out there?

Even within Chinese societies, Chinese medicine has not been given a higher status in its cultural representation either. But perhaps the following three films may give us some insight about how the cultural representation of a another system of medical knowledge can tell other stories besides health and illness. The Chinese film *Gua Sha*⁵ (Dir. Xiaolong Zheng 2001) is about an immigrant in the U.S. who is a Chinese medicine practitioner. After treating his grandchild with one of the common medical treatments known as skin scaping (gua-sha), he is accused of child abuse due to the obvious bruises and swellings on the child's body. It eventually takes a white American man to prove to the American society that the treatment is far from being harmful and is actually very effective for treating diseases. Next, in the Hong Kong film *Dumplings* (Dir. Fruit Chan, 2004), Chinese medicine is portrayed as being a

⁴ Deborah Lupton, *Medicine as Culture* (California: SAGE Publications Inc, 2003), p. 1.

⁵ Also translated as *The Treatment* in its English title.

black market practice. The practitioner (played by Bai Ling) offers dead foetus for her client, who asks for “magical rejuvenation.” Here, not only does the film serve as a good counterexample of taking traditional Chinese medicine to an extreme across the illegal/immoral border, it also associates the Chinese tradition with a sense of horror. In the more recent film entitled *Swordsmen* (Dir. Peter Chan, 2011), we have a martial arts/detective story in which the detective (played by Takeshi Kaneshiro) uses his knowledge in traditional Chinese medicine to reconstruct a crime scene and eventually saving the hero (played by Donnie Yen) from getting killed – what saves the day is nothing but an acupunctural needle. Whether this is regarded as a slow but steady progress in terms of bringing Chinese medicine to light in mainstream popular culture, or it is further mystifying Chinese medicine and its practice because, after all, swordsmen only appear in “wu xia” – a distinctive genre of fiction set in a distant time and space in Chinese history, I think these few examples serve as a good starting place for us to find out how the “Chinese” in “Chinese medicine” figures in Western societies, and what this “alternative” medical system can offer to enrich the cultural study of health and medicine.



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