

MAIJA TAMMI

Sick Photography

Representations of Sickness
in Art Photography

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Photograph by Miikka Pirinen.

Maija Tammi (b. 1985) is a Finnish artist and researcher. Her photographs and videos converse on topics around disgust and fascination, science and aesthetics. In her practice Tammi is interested in the physical and abstract places where seeing approaches a limit. Her work has been exhibited in Europe, North America and Asia. Tammi has a Masters in visual journalism and she worked as a photojournalist for six years before her artistic career. www.maijatammi.com

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Table of contents

Abstract & Acknowledgements

1.	INTRODUCTION	009
2.	PREVIOUS RESEARCH ON SICKNESS IN ART PHOTOGRAPHY	021
	2.1. Ethical and aesthetic problems	029
	2.2. Disturbing images	037
3.	SICKNESS AND ART PHOTOGRAPHY	041
	3.1. Defining sickness	042
	3.2. Kleinman's sickness, illness and disease	050
	3.3. History of sickness and (art) photography	053
	3.3.1. Sickness and Henry Peach Robinson's Fading Away	061
	3.3.2. Illness and Jo Spence's The Picture of Health?	064
	3.3.3. Disease and Raphaël Dallaporta's Fragile	068
	3.4. Applying Kleinman	071
	3.4.1. A concentration on illness	088
	IMAGES	097
4.	THE ARTWORKS	169
	4.1. Leftover, 2014	170
	4.2. White Rabbit Fever, 2016	173
	4.3. Reflection	179
5.	THE DIFFICULTY OF LOOKING	181
	5.1. Abject and its brief history	182
	5.2. Abject and disgust	187
	5.3. Abject and uncanny	190
	5.3.1. Uncanny proximity of photographs	192
	5.4. Abject art	195
	5.5. Applying abject and photography	199
	5.5.1. Systems and their borders	199
	5.5.2. A photograph as abject	204
6.	DISCUSSION	209
	6.1. Autopathographies	212
	6.2. Life in death	214
	6.3. The difficult photographs	215
	6.4. The dialogue	217
7.	WORKS CITED	225

Abstract

This artistic research scrutinises how sickness has been represented in art photography and examines new ways to approach, think about and create photographic art about sickness. The dissertation combines theoretical research and artworks. The theoretical part shows that while scholars have concentrated on the ethics of what kind of images of sickness or suffering ought to be shown or on the psychology of why some images of sickness bother viewers, most art photographers have concentrated on depicting personal illness experiences. The research applies anthropologist Arthur Kleinman's definitions of sickness, illness and disease in a diagram to examine how photographic artworks approach the topic.

To understand the functions and the meanings of the different approaches, the research draws especially from Julia Kristeva's writings on the abject. The main results of the research, artworks *Leftover* and *White Rabbit Fever*, are intertwined with the theoretical part. *Leftover* was exhibited at Photographic Gallery Hippolyte in Helsinki in January 2014, and *White Rabbit Fever* at Gallery Lapinlahti in Helsinki in September 2016. Both bodies of work have also been published as books: *Leftover/Removals* by Kehrer Verlag in 2014, and *White Rabbit Fever* by Bromide Books in 2017.

Keywords: Sickness, disease, illness, art photography, abject, Kristeva, Kleinman.

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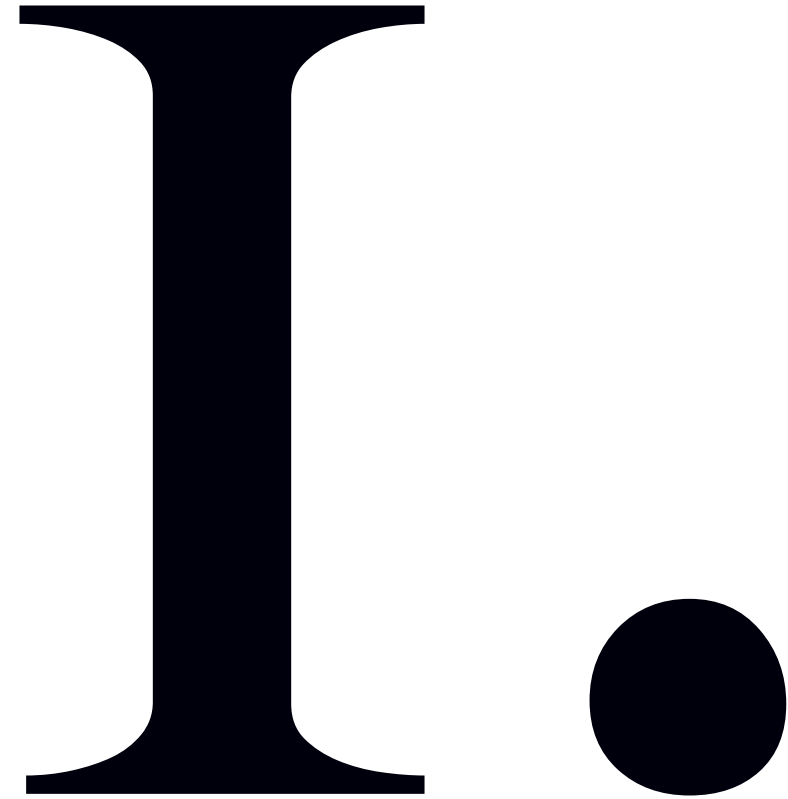
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Introduction

‘If images are like species, or (more generally) like coevolutionary life-forms on the order of viruses, then the artist or image-maker is merely a host carrying around a crowd of parasites that are merrily reproducing themselves, and occasionally manifesting themselves in those notable specimens we call “works of art”.’¹

¹ W J T Mitchell, *What do pictures want? The lives and loves of images*. The University of Chicago Press, Chicago, 2005, p. 89.



Maija Tammi: *Goitre #1*. From the series *Removals*, 2011–2013.

This dissertation starts with one photograph and ends with two photographs. The opening photograph depicts a goitre, which was removed from a human patient some minutes before the photograph was taken in 2011. For a period of two years I photographed the most common diseases at two hospitals in Tampere, Finland. I only made photographs of the surgically removed parts in clean kidney bowls, lit with an operating room light. I photographed the removed human parts with similar aesthetics to still lifes or restaurant dishes. I took photographs of goitres, tumours, cancers, gallstones, amputated parts, atherosclerosis and ectopic testis – almost anything that happened to be cut out while I was at the hospitals. The photographs were first exhibited in two group shows, at TR1 gallery in Tampere in 2012, and at The Finnish Museum of Photography in Helsinki in 2013, and the series had its first solo exhibition at Galerija Makina in Croatia in 2013.²

It is at these very first exhibitions where this dissertation begins. From the need to understand why some people found the photographs difficult to look at, becoming disturbed or uneasy while still at the same time fascinated. The need turned into a curiosity to know how art photographers portray sickness and why, and how I can make compelling art about sickness. My curiosity further grew into the dedication to research it. This is where I started in September 2013 with one big question entailing the others: How is sickness represented in art photography?

To be able to answer the *how* of my research question, I will first outline the presuppositions for this thesis and also place this dissertation in relation to previous research, and define what is meant by sickness in this study. Previous research and its key problems are examined in Chapter Two.

In this dissertation, I look at the world as a world for us, a world for humans. When I write about sickness I write about the human perspective on sickness. Representing sickness most often involves the human body, parts of the body or places where bodies are treated or cared for. The human body is inherently entangled in the definitions of sickness, and this research takes sickness as its starting point.

What I mean with art photography is artwork made for a gallery, museum or art book context. In this dissertation, I follow researcher and professor Janne Seppänen's formulation of photographic theory, where it is recognised that photographic representation is 'restless', meaning that a photograph does not just re-present something that was outside of it

2 Later the series was combined with a sister series *Leftover* and the two series were exhibited together at Photographic Gallery Hippolyte in Helsinki in 2014, at GalleriZEBRA in Karjaa in 2014, at the Photographic Centre Peri in Turku in 2015 and at the Oxford University in UK in 2015. In addition, the two series co-exist as a book *Leftover/Removals* published by Kehrler Verlag in 2014.

but that this thing outside is also present in the photograph, which in turn offers the viewer a schizophrenic position, as the viewer does not really know which one he/she is experiencing, the thing photographed or its representation.³ This research acknowledges this dilemma.

Sickness is not a new topic for visual arts. Rembrandt painted *The Anatomy Lesson of Dr. Nicolaes Tulp* in 1632, Edvard Munch *The Sick Child* in 1885–1886, and medical images have inspired artists for centuries; Francis Bacon collected medical textbooks and Leonardo Da Vinci's grotesques got their theme from medical drawings.⁴ However, according to Susan Sontag, representations of suffering in particular from a sickness are sparse:

'The sufferings most often deemed worthy of representation are those understood to be products of wrath, divine or human. (Suffering from natural causes, such as illness or childbirth, is scantily represented in the history of arts; that caused by accident, virtually not at all – as if there were no such thing as suffering by inadvertence or misadventure).'⁵

The academic Helen Thomas writes that death is the last taboo of contemporary culture, and 'thus endeavors to hide or repress its insistent manifestations'.⁶ And sickness is inherently linked to mortality. In art photography sickness has intrigued artists from Henry Peach Robinson's *Fading Away* (1858) to Jo Spence's *The Picture of Health?* (1982–1986) and to Raphaël Dallaporta's *Fragile* (2010). These artworks are examined in detail in Chapter Three. The same chapter also outlines how sickness and photography have been intertwined since the invention of photography, and analyses 67 photographic artworks, mostly contemporary, in relation to definitions of sickness, disease and illness.

Despite the fair amount of photographic works, especially over the last twenty years, there is only scant research on representations of sickness in art photography. The photographic research on the field has mainly focused on historical, medical archive photographs, for example Baer (1994), Didi-Huberman (2004), and Biernoff (2010, 2012).⁷ The newest

3 J Seppänen, *Levoton valokuva*, Vastapaino, Tampere, 2014, p. 96.
4 S Biernoff, 'Medical archives and digital culture', *Photographies* 5:2, 2012, p. 194.
5 S Sontag, *Regarding the pain of others*, Picador/Farrar, Straus and Giroux, New York, 2003, p. 40.
6 Thomas Helen (eds.), *Malady and mortality: Illness, disease and death in literary and visual culture*, Scholars Publishing, Newcastle, Cambridge, 2016, p. 2.
7 G Didi-Huberman, *Invention of hysteria: Charcot and the photographic iconography of Saltpêtière*, The MIT Press, 2004. And U Baer, 'Photography and hysteria: Towards a poetics of the flash', *Yale Journal of Criticism*, Spring94, Vol. 7 Issue 1, 1994. Also S Biernoff, 'Medical archives and digital culture', *Photographies* 5:2, 2012, p. 179–202. And S Biernoff, 'Flesh poems: Henry Tonks and the art of surgery', *Visual Culture in Britain* 11(1): 24–47, 2010.

contribution to the theme of representing sickness is by Rebeca Pardo and Montse Morcate (2016) who researched how grief, illness and death are represented in contemporary photography.⁸ Their focus is on autobiographical grief projects and on the sharing of images of illnesses in social network sites. My research looks specifically into the ways in which sickness has been represented in art photography. Therefore, photographs that were originally produced for other purposes than art, although later shown in a museum or a gallery, for example medical photographs from the 1800s, are not in the main interest of this research.

Before it can be examined how sickness has been represented, sickness has to be defined. The challenge is that the definition of sickness has varied from one decade to the next over a period of centuries, and it is still debated and negotiated. Today, in developed countries, no one can officially die of old age. The cause of death is always a disease, or a failure of an organ caused by an accident or violence. Susan Sontag died of leukaemia, Michel Foucault died of AIDS, Georges Bataille died of cerebral arteriosclerosis, Richard Avedon died of a brain hemorrhage, Dorothea Lange died of oesophageal cancer and Ansel Adams from cardiovascular disease. Robert Capa stepped on a landmine, Roland Barthes died from injuries sustained in a car accident and Diane Arbus committed suicide. As the philosopher Havi Carel writes: 'The experience of illness is a universal and substantial part of human existence.'⁹ The problem is defining what this illness is.

Because of the ongoing philosophical and practical disagreements on what is or isn't sickness, I am using anthropologist Arthur Kleinman's definitions of sickness, illness and disease as they offer a clear structure and include both the physical and cultural worlds.¹⁰ For Kleinman sickness is situated under a larger framework of suffering, and sickness includes political, economic, and institutional power structures, and is also a blanket term for both disease and illness. Disease is a biological dysfunction – thus still an interpretation of the medical practitioner. Illness is the culturally constructed, lived experience of being sick or experiencing for example a family member's illness. This categorisation of different aspects of sickness gives a fruitful starting point for dissecting the different ways of how sickness has been portrayed in art photography. The representations of illness present questions about subjective experience and the problems of representing it. Photographs of disease, on the other hand, explore the difficulty of looking; why we are disgusted or why we turn our gaze away. Representing sickness directs the attention to the otherness of the sick and to how representations affect the ways all people are treated and looked at.

8 R Pardo, M Morcate, 'Grief, illness and death in contemporary photography', *Malady and mortality: Illness, disease and death in literary and visual culture*, Cambridge Scholars Publishing, Newcastle, 2016, p. 245–251.
9 Havi Carel, *Phenomenology of illness*. Oxford University Press, Oxford, 2016, p. 1.
10 A Kleinman, *The illness narratives: Suffering, healing and the human condition*, Basic Books, New York, 1988, p. 3–8.

Nonetheless after the *how* there is still a task left, and the task is to try to understand why sickness is depicted the way it is, and why photographs of sickness test our limits of looking. 'It is too much, it is too much', photographer Torben Eskerod repeated, when he saw a woman with worms squirming in the wounds on her scalp. Eskerod was photographing life at Vita, which is a centre for unwanted, sick and mentally ill people in Brazil.¹¹ Photographs that show things that are 'too much' can be approached through the concepts of abject, disgust, and uncanny.

These terms are introduced in Chapter Five, which also scrutinises the disgust and fascination that arises from photographs showing sickness. The chapter leans on Julia Kristeva's conceptualisation of abject in her book *Powers of Horror: An Essay on Abjection*, published in 1980. The concept of abject can help to understand some aspects of the uncomfortable feeling people get when they encounter something that is disturbingly outside the physical or cultural order. The chapter also looks into why photographs in particular are so potent at being abject.

If looking at photographs of sickness has the power to make the viewer uneasy, is there a way to regain control over this effect? As Susan Sontag puts it: 'Real art has the capacity to make us nervous. [...] Interpretation makes art manageable, comfortable.'¹² In this research I plan to do both: create art and also make photographic works manageable. Chapter Four introduces my artworks *Leftover* (2014) and *White Rabbit Fever* (2016).

This dissertation is artistic research, sometimes also called practice-based research or studio-based research. Finnish artist–researcher Teemu Mäki lists four reasons for an artist to conduct research in his article *Art and Research Colliding* (2014). In short the reasons are: to make better art, to understand and enjoy art more, to explain art better, and to understand more about the world through art and then to change the world with art:

'becoming aware of theories previously unknown is like extending one's capability of hearing or seeing – the reality expands and becomes more perceivable. [...] Our existence, our lifeworld, is a totality in which the physical reality and hard facts mix with our poetic or rational interpretations of them and with visions of that which could or should be.'¹³

Thus, as Mäki writes, conducting research does not guarantee that the artist will make better art works, but it does increase the odds.¹⁴

11 J Biehl, *Vita. Life in a zone of social abandonment*, University California Press, Berkley and Los Angeles, 2005, p. 38.
12 S Sontag, *Against interpretation*, Penguin Books, England, (orig. 1961), 2009, p. 8.
13 T Mäki, 'Art and research colliding', *Journal for Artistic Research*, 5, 2014, accessed March, 10, 2016, www.researchcatalogue.net/view/49919/49920/0/0
14 T Mäki, *Journal for Artistic Research*, 2014.

Artistic research does not only aim at making potentially good artworks, its aim is to create new knowledge.¹⁵ Though the type of the knowledge is not limited to classical knowledge: ‘artworks are not statements but phenomena to be understood. Artworks can and do provide insight into the human experience, but as possibility, not logical or scientific truth: as claims rather than certainty.’¹⁶ As artist-researches Harri Pälviranta writes, when in natural sciences the research is based on the separation and distance of the researcher and research object, in artistic research the two go hand in hand.¹⁷

At the time of this dissertation, artistic research has been conducted for over thirty years, mostly in Australia, UK, and Scandinavia, Finland being the pioneer.¹⁸ Although administratively possible since the end of 1980s in Finland, the first artistic dissertation in photography in Finland was Taneli Eskola’s dissertation in 1997. How artistic research is conducted differs by countries and by disciplines, for example in the UK, academic perspective can be seen to be emphasised, whereas in Scandinavia it’s artistic values.¹⁹ Within disciplines what differs the most is the role of artwork in the research, and this in turn depends on how art is understood within the discipline – for example as process, research, originality or criticality – and what is seen as the final artwork.²⁰

During the two decades of active artistic research there have been nine artistic dissertations in photography in Finland: Taneli Eskola (1997), Kristoffer Albrecht (2001), Juha Suonpää (2002), Jan Kaila (2002), Petri Anttonen (2004), Tapio Heikkilä (2007), Harri Pälviranta (2012), Marjaana Kella (2014), and Pekka Luukkola (2016). Eight of these nine artistic dissertations were done at Aalto University, School of Arts, Design and Architecture, in the department of Media, which includes fine art photography. In the department, the final artworks are presented as either art exhibitions or art books, which are evaluated similarly to the written research.²¹

15 M Hannula, J Suoranta, T Vadén, *Artistic research – theories, methods and practises, Academy of Fine Arts*, Helsinki, Finland and University of Gothenburg, Cosmoprint, Espoo, 2005, p. 151.
16 S AR Scrivener, ‘Visual art practise reconsidered: Transformational practice and the academy’, in *The Art of Research. Research practices in art and design*, M Mäkelä, S Routarinne S (eds.), Gummerus kirjapaino, Jyväskylä, 2006, p. 171.
17 H Pälviranta, *Toden tuntua galleriassa*: väkivaltaa käsittelevän dokumentaarisen valokuvataiteen merkityksellistäminen näyttelykontekstissa, Aalto ARTS books, Musta Taide, Keuruu, 2012, p. 142.
18 J Kortti, ‘Taiteellinen tutkimus ja audiovisuaalinen kulttuuri’, *Lähikuva* 3/2013, Tammerprint Oy, Tampere, 2013, p. 3. Also M Mäkelä & S Routarinne, ‘Connecting different practices’ in *The Art of Research*, Gummerus kirjapaino, Jyväskylä, p. 10–39, 2006, p. 14.
19 A Arlander, ‘Taiteellisesta tutkimuksesta’, *Lähikuva* 3/2013, Tammerprint Oy, Tampere, 2013, p. 22.
20 Arlander, *Lähikuva*, 2013, p. 22.
21 The Leftover exhibition at Hippolyte Gallery was evaluated and approved as a part of this dissertation by Professor Jan Kaila and Doctor of Arts Harri Pälviranta, and the White Rabbit Fever exhibition at Gallery Lapinlahti by Professor Jan Kaila and Doctor of Arts Teemu Mäki.

What is required from an artistic dissertation at Aalto University is that the produced artworks are in dialogue with theoretical research, meaning that artworks and theoretical research interact and influence each other. The dialogue’s outcome is the new knowledge: the new way of seeing the research object and its connections to the world manifested in the artworks.²² At Aalto University each dissertation, including the one at hand, has to negotiate and explain its own relationship between the research and the artworks. For example Harri Pälviranta keeps the artist and the researcher positions separate in his dissertation, but the two roles collaborate while making separate projects.²³ In Maiju Loukola’s dissertation in performing arts, she describes artistic research as a correspondence between the visual and verbal argumentation, and states the biggest challenge is to make this correspondence visible.²⁴ In this dissertation the artworks and research illuminate each other: artworks express the ideas brought forth in the research, and the research in turn gives inspiration to the artworks.

In comparison to other sciences, artistic research is still young and developing, and the relationship of art and academia is constantly contested and negotiated.²⁵ Consequently, the discussion about the benefits and the reason for combining research and art is ongoing, and also the artist–researcher double role has been questioned.²⁶ Scholar James Elkins questions even the use of terms ‘research’ and ‘new knowledge’ in artistic research as the motivation to use these terms was in the first place economic.²⁷ Elkins would replace the terms with a different vocabulary that arises from the practice of art itself instead of borrowing from other disciplines. However, according to Elkins, borrowing from and merging with other sciences is beneficial in a larger scale:

‘[S]tudio-art PhD creates the possibility for whole new kinds of interdisciplinary, transdisciplinary, and other unnamed configurations, because it does not add kinds of scholarships to one another: it mingles scholarship with expressive work.’²⁸

Thus, as Schwab and Borgdorff write in *The Exposition of Artistic Research*, the mingling of art and academia require ‘exposing’ to be consistent:

22 Hannula et al., *Artistic Research*, 2005, p. 114.
23 H Pälviranta, *Toden tuntua galleriassa*, 2012, p. 143.
24 M Loukola, *Vähän väliä (V/ä/h/ä/n v/ä//i/ä)*: näyttämön mediaalisuus ja kosketuksen arkkitehtuuri, Aalto University publication series, 2014, p. 20–21.
25 H Borgdorff, M Schwab (eds.), *The exposition of artistic research: Publishing art in academia*, Leiden University Press, 2014, p. 9.
26 H Pälviranta, *Toden tuntua galleriassa*, 2012, p. 142.
27 J Elkins (ed.), *Artists with PhDs: On the new doctoral degree in studio art*, New Academia Publishing, Washington, DC, 2009, p. 111.
28 J Elkins, *Artists with PhDs*, 2009, p. 279.

‘Lacking established languages and disciplinary frameworks for the multiplicity of possible crossings, it seems that each and every artistic proposition needs to have the capacity to “expose” itself as research in order to create a link to academia.’²⁹

Currently there are around 280 institutions offering studio-art PhD programs.³⁰ Elkins predicts that studio-art PhD will spread worldwide and become the required degree for teachers.³¹ Also global standards for art-based PhDs are developing.³² For example Hannula, Suoranta and Vadén (2005) have collected and evaluated principles for artistic research so that it is scientifically mature and reliable.

The reliability of artistic research lies, according to Hannula et al., in constant criticism and openness, self-reflectivity and self-criticality. By this they mean that the artist-researcher not only makes evident for herself and for the readers the presuppositions, interests and goals of her research but makes visible the entire process of thinking and creating, from the initial research question to the conclusions.³³ Hannula et al. underline that this should be the case ‘even when it [the research] contains intuitive jumps or inexplicabilities within the artistic creative process.’³⁴ Mäkelä and Routarinne (2006) state that it is inevitable to use language to be able to communicate the new knowledge that the artworks produce: ‘In academe, the artist-researcher cannot hide behind the robe of a mute artist.’³⁵

Artistic research also acknowledges that the research alters and changes the research object and the world; the artist-researcher is not an outside observer of the research object, but a part of the object and also the main tool for the research.³⁶ The aim of artistic research is not to give measurable, definite answers but to understand. To be able to understand, my research trespasses from art and photography research into anthropology, psychoanalysis, psychology, social psychology, sociology, neuroscience and biology. The end result is an amoeba, which is how the artist–researcher Outi Turpeinen sees the artistic research process: ‘everything interplays with everything and where interpretations happen in a context’.³⁷

Within this framework of the Scandinavian tradition of artistic research, I set out to develop a version of the dialogue between research and artworks, and to extract knowledge out of the amoeba. And this amoeba as a one-cell creature replicates through binary fission, copying itself and evolving through mutations eternally, provided the living space and food (for thought).

In the next chapter I look into previous research on representations of sickness in art photography. I aim to trace what kind of questions scholars have been occupied with and what are the major discussions on the topic.

29 H Borgdorff, M Schwab (eds.), *The exposition of artistic research*, 2014, p. 9.

30 The ‘Florence principles’ on the doctorate in the arts, European League of Institute of the Arts (ELIA), Dec 2, 2016, accessed May 3, 2017, www.elia-artschools.org/userfiles/File/customfiles/1-the-florence-principles20161124105336_20161202112511.pdf

31 J Elkins, *Artists with PhDs*, 2009, p. 278.

32 The ‘Florence principles’ on the doctorate in the arts, European League of Institute of the Arts (ELIA), 2016.

33 Hannula et al., *Artistic Research*, 2005, p. 20, 44, 49.

34 Hannula et al., 2005, p. 160.

35 M Mäkelä, S Routarinne, ‘Connecting different practices’, *The art of research*, 2006, p. 25.

36 Hannula et al., *Artistic research*, 2005, p. 159.

37 O Turpeinen, ‘The interplay of art and reseach’, in *The art of research*, M Mäkelä, S Routarinne Sara (eds.), Gummerus kirjapaino, Jyväskylä, 2006, p. 121.

2.

Previous Research
on Sickness
in Art Photography

Previous research on representations of sickness in photography, and in art photography, is dispersed amidst different academic research fields and approaches. This chapter aims to outline the biggest academic contributions to the topic of representing sickness in art photographs while Chapter Three examines actual artworks. However, because of the scarcity of research concentrating solely on representations of sickness I have also included research on representations of suffering, to be able to introduce the main approaches and the main problems from a representational point of view. In addition, to give an even broader perspective of the topic, I have included three art book anthologies: *Hospice: A Photographic Inquiry* (1996), *Clinic* (2008), and *Body at Risk, Photography of Disorder, Illness and Healing* (2005). The first two art books are commissioned anthologies, while *Body at Risk* is a collection of ten classic documentary essays spanning from early 1900s to early 2000s.

I am aware that it cannot be presupposed that sickness always means also suffering, however the two terms are closely related in many cases. As anthropologist Paul Farmer writes: ‘Almost all of us would agree that premature and painful illness, torture and rape constitute extreme suffering.’³⁸ In addition, in this research suffering is understood socially, as an outcome of political, economic, and institutional decisions instead of as a mere personal tragedy.³⁹ I will first briefly introduce the previous research at large, and then tighten the perspective and scrutinise some of the key issues more in depth.

Academic and critic Susan Sontag has been one of the most significant contributors to the theme. She has written extensively, although separately, on photography and on sickness; *On Photography* (1977), *Illness as Metaphor* (1978), *AIDS and Its Metaphors* (1988), and *Regarding the Pain of Others* (2003). In her books, she scrutinises the effect of seeing images of suffering but also examines the way in which some diseases have been romanticised in literature and how illness has been used as a metaphor. It was especially her critique on photographs depicting suffering that had a considerable effect on photography artists in the 1980s. Sontag strongly questioned the morality of photographing for example ‘freaks’ (by Diane Arbus), and called for responsibility of the photographer because photographs are not just objective data but also ‘items of psychological science fiction’⁴⁰ which modify the way people see the world. She also pointed out that socially concerned photographs cannot reveal any ‘truth’ but are used for various means depending on their context.⁴¹

38 A Kleinman, V Das, M Lock (eds.), *Social suffering*, University of California Press, Berkeley, Los Angeles, London 1997, p. 261.

39 A Kleinman, *Writing at the margin. Discourse between anthropology and medicine*, University of California press, Berkley and Los Angeles, California, 1997, p. 15.

40 S Sontag, *On Photography*, Picador, Farrar, Straus and Giroux, New York, (orig, 1977), 2011, p. 163.

41 S Sontag, *On Photography*, 2011, p. 105.

In the 1980s, artist and activist Jo Spence made various photography series and wrote in abundance about her own illnesses, breast cancer and leukaemia. Spence is one of the best-known photographers to make art on illness and sickness. Her political art aimed to problematise Western medicine and to question the representations of the sick body. Her works will be examined more in detail in Chapter Three.

In the mid-1990s, the Corcoran Gallery of Art in Washington and the National Hospice Foundation commissioned Nan Goldin, Jack Radcliffe, Sally Mann, Kathy Vargas and Jim Goldberg to make photographic essays of hospice care. The result was an exhibition and also the book *Hospice: A Photographic Inquiry*, published in 1996. Major funding for the exhibition and book came from the pharmaceutical and consumer product company Warner-Lambert. In the book, Goldberg’s photographs examine his own father’s death, Vargas’ photographs are composite images about loss and remembering, Nan Goldin’s photographs portray hospice patients in New York and Radcliffe’s in York, Pennsylvania. Sally Mann’s black and white still life photographs aim to mediate between life and death. The photography scholar Jane Livingston mentions in the introduction of the book that the commissioned exhibition and the book were ‘a high-risk experiment’, as there was no guarantee how combining hospice care and photography would work together⁴².

Researcher Deborah Lupton examines in her book *Medicine as Culture; Illness, Disease and the Body in Western Societies* (1994) the socio-cultural dimensions of medicine, including its representations in elite and popular culture. Her book combines sociology, anthropology, history and cultural studies. Although Lupton concentrates mostly on literary representations and usage of metaphors she also touches on the visual representations of sickness. According to her: ‘[i]mages of disease remain relatively stable over centuries, influenced only slightly by shifting popular or medical views’⁴³.

Lupton also states that positive representations of doctors and scientific medicine dominate over negative ones in news and fiction alike: ‘In popular media representations, medical technology, in particular, is singled out as the apotheosis of medical magic’⁴⁴.

In social sciences, the British scholar Alan Radley (2002) has scrutinised the role and function of portraying sickness and the sick in a society.

42 D Andre, P Brookman, J Livingston (eds.), *Hospice, A Photographic Inquiry*, Corcoran Gallery of Art and the National Hospice Foundation, A Bulfinch Press Book, Little Brown and Company: Boston, New York, Toronto, London, 1996, p. 15.

43 D Lupton, *Medicine as culture: Illness, disease and the body in Western societies*, Second Edition, Sage, London, 2003, p. 78.

44 D Lupton, *Medicine as culture*, 2003, p. 57.

According to Radley representations of the ill disturb the healthy, but these disturbing representations, works of illness, also show a new way to know and to look at the world instead of just generating sympathy in the viewer.⁴⁵

The cultural and literary historian Sander L. Gilman has written numerous books on the medical and cultural representations of disease, and especially the diseased ‘other’. In *Disease and Representation* (1988) and *Health and Illness, Images of Difference* (1995) Gilman traces the cultural stereotypes of representing disease, in other words how specific diseases have been imagined and what kind of images have been produced for example in newspaper illustrations, medical textbooks and also in fine art. For Gilman, the diseased is always the ‘other’, onto whom we project our own anxieties of losing our self-control and ultimately collapsing.⁴⁶ One of the stereotypes Gilman traces in his historical analysis is the health/ill division, which according to him is very identical to beautiful/ugly division in Western cultures. Beautiful patients, mostly female and young, will get better and do as the doctor tells them, ugly people will die.⁴⁷ This is also the stereotype than many artists with HIV and AIDS wanted deliberately to wrestle with. Gilman has looked into public health posters about HIV and AIDS and points out the deliberate aesthetisation of body; the posters show healthy, beautiful people potentially at risk, not diseased bodies or dying people.⁴⁸

Carol Squiers curated an exhibition and a catalogue *Body at Risk, Photography of Disorder, Illness and Healing* in 2005. The exhibition and catalogue introduce works of sixteen documentary photographers, in the 1900s and early 2000s, who depicted the human body in relation to sickness and health. The book includes for example W. Eugene Smith’s *Maude Callen, Nurse Midwife* and Sebastião Salgado’s *The End of Polio*. The book is a collection of documentary photography essays accompanied by thorough background information on each topic to give context to the portrayal of the suffering ‘other’. Squiers writes that she deliberately chose photography essays that do not look at sick people primarily as victims.⁴⁹

While Squiers was interested in how sick people are depicted in photographs, Reinhardt et al. questioned a year later, in 2006, whether images of suffering should be shown in the first place. They edited a book *Beautiful Suffering: Photography and the Traffic of Pain*, in which they

45 A Radley, *Works of illness: Narrative, picturing, and the social response to serious disease*, Ashby-de-la-Zouch, InkerMen Press, 2009, p. 107.
46 S L Gilman, *Disease and representation: Images of illness from madness to AIDS*, Cornell University Press, Ithaca, N.Y., 1988, p. 2.
47 S L Gilman, *Health and illness, Images of difference*, Reaktion Books, 1995, p. 183.
48 S L Gilman, *Health and illness, Images of difference*, 1995, p. 115–119.
49 C Squiers, *The body at risk. Photography of disorder, illness and healing*, International Center of Photography, New York, University of California Press, 2005, p. 9.

problematised the mere visibility and aesthetics of the horrible images of suffering and disasters. The book concentrates on images of war, terrorism and torture.

In 2008, the French art director Rémi Faucheux curated the documentary art photography book *Clinic*. The book consists of commissioned works by eleven contemporary photographers whose works examine the medical world. The photographers include Christophe Bourguedieu, Stefan Ruiz, Constant Anèe, and Ville Lenkkeri, to name a few. Art historian Michel Poivert writes in the book’s introduction that ‘the world of hospitals, of disease and treatment, of the human body and suffering, is an ambitious gamble.’⁵⁰ He writes that the representations shown in the book land in a field where institutions have their own desired message of great medical progress to tell and on the other end are those who criticise this impassionate affliction. According to Poivert, the importance of the artistic approach on the topic comes from its ability to escape this antagonism, to have no pre-written agenda. However, anthropologist Marie-Christine Pouchelle reminds us in her essay in the same book that, despite this, none of the photographs in the book are ‘benign’, as they all take part in constructing and deconstructing the institution of the clinic: science, emotions, actions and aesthetics.⁵¹

The end of the book has a separate section titled *Useful Photography #Medical*, a collection of old medical photographs from ‘an era when medical machines were still mostly constructed from enamelled iron’ taken out of their original context.⁵² The series is collected and edited by Hans Aarsman, Claudie de Cleen, Julian Germain, Erik Kessels and Hans van der Meer.

In 2011, the academic journal *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* published a special issue with six articles examining the portrayal of health and illness in the arts. The focus of the issue is to look at how art intertwines with illness. In the journal, art is understood broadly and especially from the point of view of how it can communicate the illness experience or influence the ways of being ill. In the journal, sociologist Susan E. Bell describes and analyses Anna Schuleit’s two public art performances in former mental institutions.⁵³ Bell emphasises how Schuleit’s art performances give a voice to those who normally wouldn’t have one and how they disrupt the expected representations of mental institutions. Four of the articles in the journal concentrate on visual representations.

50 M Poivert, ‘Clinic’ in *Clinic*, Images en Manoeuvres Editions, Marseille, 2008, p. 4.
51 M-C Pouchelle, ‘Clinic’ in *Clinic*, Images en Manoeuvres Editions, Marseille, 2008, p. 12–13.
52 R Faucheux (ed.), *Clinic*, 2008, p. 183.
53 S E Bell, ‘Claiming justice: Knowing mental illness in the public art of Anna Schuleit’s “Habeas Corpus” and “Bloom”’, *Health: An Interdisciplinary Journal for the Social Study of Health, Illness & Medicine* 15(3), 2011, p. 313–334.

In the journal the artist Deborah Padfield claims that art photographs can communicate pain better than mere language, and proposes art photographs be used to enhance communication about pain in a doctor-patient relationship.⁵⁴ She is looking at photographs' representational ability from a practical point of view in a clinical context.

A personal illness experience is emphasised in photographer Terry Dennet's article that introduces Jo Spence's auto-therapeutical strategies. These strategies include a photography-based method to cope with breast cancer. Dennet analyses Spence's photography projects as representational strategies that can help the ill to cope with their illness.⁵⁵ However, Spence's photographs are more than just a personal coping strategy, they are also deliberately political and strive to question how illness and ill people are seen by the healthy and what kind of roles are offered to the ill in society.

Researchers Henriksen et al. offer a spectator's point of view in their article, in which they study the visual aesthetics of Sara Bro's video montage representing her breast cancer experience. The writers scrutinise the montage in relation to Roland Barthes' writings and bring up the effectiveness of 'disguise' in Bro's visuals, for example making going to the hospital to look like going to a concert. This, according to Henriksen et al., awakens curiosity and invites fascination in the viewer but also challenges the expected representations of the ill.⁵⁶

The researcher Mary O'Neill studies the viewer experience at its limits, at the point when images bother viewers. She examines, through specific art works, why some photographs depicting dead people disturb us. O'Neill concludes with a distinction that only those representations of the dead that make us picture or think about our own or our loved ones' possible deaths disturb us.⁵⁷ O'Neill is trying to understand the psychological effects of looking at images of dead bodies in an art context.

One of the most recent books on the representations of sickness is *Malady and Mortality. Illness, Disease and Death in Literary and Visual Culture* (2016) edited by Helen Thomas. The book is a collection of articles that examine how illness has been represented in visual and literary

54 D Padfield, "Representing" the pain of others' in *Health: An interdisciplinary journal for the social study of health, illness & medicine* 15(3), p. 241–257, 2011, p. 242.

55 T Dennet, 'Jo Spence's auto-therapeutic survival strategies', in *Health: An interdisciplinary journal for the social study of health, illness & medicine* 15(3), 2011, p. 223–239.

56 N Henriksen, T Tjørnhøj-Thomsen, H P Hansen, 'Illness, everyday life and narrative montage: The visual aesthetics of cancer in Sara Bro's Diary', in *Health* 15(3), 2011, p. 277–297.

57 M O'Neill, 'Speaking to the dead: Images of the dead in contemporary art', in *Health* 15(3), 2011, p. 299–312.

culture. The articles range from research on medical humanities, patient experience, poetry, and graphic design to film and photography. Three of the articles concentrate on photography.

In the book Fiona Johnstone analyses Mark Morrisroe's AIDS related self-portraits that, according Johnstone, negotiate between an erotised, active body and a passive medical subject. Lorna Warren and Julie Ellis examine with concrete cases how family photographs of terminally ill or dead people are a part of the family's identity building. Researchers Rebecca Pardo and Montse Morcate present an overview on how grief, illness and death are represented in contemporary photography. They note in their short article that illness and death have become increasingly present in arts. Their focus is on the autobiographical grief projects, which can also include projects on chronic and terminal illnesses. Pardo and Morcate differentiate between three ways photographers often approach the subject, the ill person: paying homage to the subject by constructing a personal narrative of the ill person, showing the photographer's own grief and thirdly facing and negotiating the photographer's own relationship to malady and mortality⁵⁸.

Pardo and Morcate conclude that artworks can help artists to personally overcome grief, and that these documentation projects often start instinctively. They add that, in addition, artworks change how sickness can be seen and experienced:

'By focusing upon the pain and suffering of the photographer and the subject, these photographs question the taboos of the traditional family album, recording end-of-life situations within hospital environments and/or at the mercy of medical treatment.'⁵⁹

According to Pardo and Morcate's analysis, the most common diseases documented are cancer, dementia and AIDS.⁶⁰ In a separate article and on-going project, Pardo and Morcate examine the sharing of illness and grief images on social network sites. They write that photographing illness in a family setting is becoming more acceptable.⁶¹

Notwithstanding the academic research's dispersion amidst different academic fields, the same two (moral) questions reoccur when it comes to photographs of sickness in an art context:

58 R Pardo, M Morcate, 'Grief, illness and death in contemporary photography' in *Malady and mortality: Illness, disease and death in literary and visual culture*, Newcastle, Cambridge Scholars Publishing, p. 245–251, 2016, p. 248.

59 R Pardo, M Morcate, *Malady and mortality*, 2016, p. 251.

60 R Pardo, M Morcate, *Malady and mortality*, 2016, p. 249.

61 R Pardo, M Morcate, 'Illness, death and grief: daily experience of viewing and sharing digital images', in *Digital photography and everyday life*, E Cruz and A Lehmuskallio (eds.), Routledge, London and New York, 2016, p. 70–85.

Should images of suffering be shown (in an art context)?

Why is it so uncomfortable to look at them?

Mieke Bal writes for example that it is morally unfair to aesthetically enjoy someone’s suffering. She uses as an example Nicholas Nixon’s photograph of Tom Morat; in the photograph, Morat is looking at his naked and AIDS-ridden upper body from a mirror. Bal writes:

‘twenty years ago this man was dying, and I am enjoying myself at a photography exhibition. And I am the one to benefit? Something is just not right.’⁶²

Carol Squiers, on the other hand, carefully articulates in the introduction of *The Body at Risk*, which shows photography essays of mainly poor or diseased people, that it is important to see these images as they, contextualised with social and political texts, can increase the understanding of the world. She underscores that the photographers did not look at the diseased and the poor primarily as victims or as ‘figures of abjection’, and that none of the photographs were taken primarily for aesthetic reasons, although the ‘seductive qualities’ can make the images more persuasive.⁶³

In her article *Speaking to the Dead*, Mary O’Neill discusses Andres Serrano’s *Morgue* photographs, asking if they do violence to the subjects of the images or whether they give positive attention to the dead bodies. However, O’Neill’s main interest lies in the psychology of the viewing, that is, why certain types of depictions disturb.

‘I will argue that images of the dead are acceptable as long as they do not cause pain to the living, as in a video game or a fiction, or are seen as other and distant.’⁶⁴

Additionally, many researchers seem to have difficulty in defining the role of photography: what is a photograph, a representation of something or an object in itself, science or art, or all of them at once? According to Sontag this problem is the source of the moral debates:

62 M Bal, ‘The pain of Images’ in *Beautiful suffering: Photography and the traffic of pain*, Reinhardt, Edwards & Duganne (eds.), Williams College Museum of Art and University of Chicago Press, Chicago, p. 94–115, 2006, p. 94.
63 C Squiers, *The body at risk. Photography of disorder, illness and healing*, International Center of Photography, New York, University of California Press, 2005, p. 9–11.
64 M O’Neill, ‘Speaking to the dead: Images of the dead in contemporary art’, *Health* 15(3), p. 299–312, 2011, p. 300.

‘The dual powers of photography – to generate documents and to create works of visual art – have produced some remarkable exaggerations about what photography ought to or ought not to do.’⁶⁵

Next I will look more in detail into the two questions presented.

2.1. Ethical and aesthetic problems

Should the images of suffering be shown (in an art context)? Susan Sontag’s answer to the question could be paraphrased as ‘no, but sometimes yes’. According to Sontag the constant flow of images of suffering and war has a numbing effect, and the photographs of suffering causes passivity in people instead of encouraging social action. Sontag states that only photographs which shock can potentially assign blame and alter conduct.⁶⁶ But, the horrifying images are often only effective once. Sontag writes in *On Photography* that when she saw the images of the concentration camps of Bergen-Belsen and Dachau for the first time, something broke:

‘Some limit had been reached, and not only that of horror; I felt irrevocably grieved, wounded, but part of my feelings started to tighten; something went dead; something is still crying.’⁶⁷

Sontag continues that after one has seen such images once, and then more and more of them, one becomes anesthetised.

However, this numbing caused by the repetitive viewing of traumatic images can also be used as a visual method to purposefully make images less effective and to integrate them into everyday life. Andy Warhol, whose *White Burning Car III* repeats a photograph of a crashed and burning car, said in an interview in the 1960s that gruesome photographs lose their effect when they are repeated over and over again.⁶⁸ In general, it seems to be easier for researchers to agree on what repetition does to images, than to say how photographs of suffering ought to be shown.

65 S Sontag, *Regarding the pain of others*, 2003, p. 76.
66 S Sontag, *Regarding the pain of others*, 2003, p. 81.
67 S Sontag, *On Photography*, Picador. Farrar, Straus and Giroux, New York, (orig, 1977), 2011, p. 20.
68 H Foster, *The return of the real. The avant-garde at the end of the century*, MIT Press, Cambridge, Massachusetts, London, 1996, p. 131.

For Sontag, photographs of suffering give mixed signals: ‘Stop this it urges. But it also exclaims, “What a spectacle!”’⁶⁹ So while simply showing a photograph of suffering can be morally problematic, it is even more problematic when the photograph is aesthetically (too) pleasing and hung at an art gallery. Mark Reinhardt, a professor of political science, asks: ‘Can photography say anything else except “What a beautiful world”’?⁷⁰ For him, the very problem with aestheticising suffering is making it agreeable to the viewer. He writes that perhaps when people see suffering in a mesmerisingly beautiful image they really don’t want the scene to change.⁷¹ For Reinhardt photographs of suffering fail ethically and politically when the response they invite from the viewer is less than mere acknowledgement.⁷²

One example of this debate is Diana Arbus’ photographs of giants, dwarfs, and mentally challenged people. It is still debated if her intentions were acceptable or not. According to Michael Fried:

‘The charge, briefly put, has been that Arbus typically exploited her sitters by using photography to reveal aspects of the latter’s appearance that they could not have imagined would make the impression on others that those aspects inevitably do.’⁷³

The British art historian Jonathan Friday constructs the same type of value structure in his writing as Reinhardt. Friday states that documentary photography ‘is rightly thought of as an art when it manages to aesthetically transform the human evils it depicts into valuable meaning.’⁷⁴ Friday is looking for a justification for an artist to show extreme human suffering.

The art historian James Elkins brings up in his book *What Photography Is* (2011) a discussion originally described by curator Julian Stallabras, which led to the exclusion of photojournalist Simon Norfolk’s photograph of a bloodied baby from a museum exhibition. According to Elkins, the curator and the artist were worried that the large scale would state that the image is fine art.

‘The problem was that if the disturbing photograph were enlarged, that would imply it was art, and art itself might appear as an irresponsible posture, riding on atrocity; and it might even have seemed that Norfolk’s photo needed to be enlarged to qualify as art.’⁷⁵

69 S Sontag, *Regarding the pain of others*, 2003, p 77.

70 M Reinhardt, H Edwards and E Duganne (eds.), *Beautiful suffering*, 2006, p. 20.

71 Reinhardt et al., *Beautiful suffering*, 2006, p. 29.

72 Reinhardt et al., *Beautiful suffering*, 2006, p. 31.

73 M Fried, *Why photography matters as art as never before*, Yale University Press, New Haven and London, 2008, p. 208.

74 J Friday, ‘Demonic curiosity and the aesthetics of documentary photography’, *British Journal of Aesthetics*, vol 40(3), July 2000, p. 358.

75 J Elkins, *What photography is*, Routledge, New York and London, 2012, p. 187.

The authors of *Beautiful Suffering* struggle with the same problem; Mieke Bal states in the book that the only un-condemnable way to show suffering as art is to make political art. She is concerned with the moral unfairness of aesthetically enjoying someone’s suffering.⁷⁶ Reinhardt et al. note that no matter how critical the photos are of the suffering, the images still repeat the actual suffering depicted in them.⁷⁷ For James Elkins the problem is even more fundamental and he sees no possible resolution:

‘This discussion of aesthetics and politics is endless, because there is not yet any way to stand back and judge the difference; there is no third term, no third position, no sensible combination.’⁷⁸

This ‘yet’ can also just mean that more research is needed. The authors of *Beautiful Suffering* offer time (inviting time for contemplation) as a solution to their moral dilemmas of showing photographs of harrowing events in their curated exhibition:

‘How can photographers, curators and editors slow down habits of consumption and encourage viewers to think more carefully about what they see and, by extension, what they cannot see? This exhibition is one effort to do that.’⁷⁹

Still, inviting viewers to linger and ponder with images of suffering does not necessarily change people’s behaviour or thoughts. This question of why seeing extreme suffering in photographs only seldom leads to action can be approached from a different point of view, outside of photography research. Professor of psychology and neuroscientist Joshua Greene scrutinises in his book *Moral Tribes: Emotion, Reason, and the Gap Between Us and Them* the reluctance of people to help unknown others in far away places, and also why global problems in general are so difficult for humanity. Greene’s main argument is that people are evolutionarily cooperative, but mainly within their own tribes and immediate surroundings, as people have had to fight off other tribes.

Greene uses as an example that if we see a child drowning in a pond while we are strolling through a park, even if it would ruin our five hundred dollar suit, of course we will try to save the child. However, even if we would know for sure that with the same five hundred dollars we could save a child drowning somewhere else, it is not ‘of course’ anymore.⁸⁰ Our gut reactions, ‘emotional automatic settings’, make us fair and just within our

76 M Bal, ‘The pain of images’ in *Beautiful suffering*, Reinhardt, Edwards, Duganne (eds.), Williams College Museum of Art and University of Chicago Press, Chicago, p. 94–115, 2006, p. 94.

77 Reinhardt et al., *Beautiful suffering*, 2006, p. 10.

78 J Elkins, *What photography is*, 2012, p. 188.

79 Reinhardt et al, *Beautiful suffering*, 2006, text following the plate 41.

80 J Greene, *Moral tribes: Emotion, reason and the gap between us and them*, Atlantic Books, London. 2015, p. 258.



Jeff Wall: *Dead Troops Talk* (detail), 1992.

own communities. For global problems what is needed is a moral thinking that overrides the emotional automatic settings, which have evolved to put ‘us’ before ‘them’ instead of thinking of all humanity.⁸¹ What is needed is metamorality, by which Greene means:

‘a global moral philosophy that can adjudicate among competing tribal moralities, just as a tribe’s morality adjudicate among the competing interests of its members.’⁸²

This is a moral challenge also for photography. Greene points to studies that look to measure how much sympathy people feel, and how willing they are to help, if a person is identified or not. It turns out that people are willing to donate more money to one identified child versus eight unidentified children in need of the same medical help.⁸³ What Sontag, Reinhardt, Friday and Bal are asking and hoping photographs of suffering to do, can be seen as evoking Greene’s metamorality. How photography can help in doing this is a complex question.

For Susan Sontag, the one image that can really say ‘stop this’, is a completely staged art photograph depicting war. In her book *Regarding the Pain of Others*, Sontag is looking for an antidote to beautiful images of war and terror and finds one. It is Jeff Wall’s *Dead Troops Talk* (*A Vision After an Ambush of a Red Army Patrol near Moqor, Afghanistan, Winter 1986*) made in 1992. In the large, four-metre wide, completely staged photograph, the dead soldiers are alive and talking to one another. No one is acknowledging the camera, and for Sontag this is the crux of the photograph: the soldiers have no reason to want to look at the camera, because:

‘We don’t get it. We truly can’t imagine what it was like. We can’t imagine how dreadful, how terrifying war is; and how normal it becomes. Can’t understand, can’t imagine.’⁸⁴

This lack of empathy, the inability to imagine, is also a problem when it comes to representations of sickness, especially long-term illnesses. The philosopher Havi Carel underscores that studies show that the third-person view of illness overestimates the impact of being ill to one’s general well-being and happiness⁸⁵. She gives, as one example, a study made in 1997, where healthy interviewees had marked 83 states of illness as ‘worse than death’:

‘However, people who live with these conditions report only slightly diminished level of well-being as their healthy counterparts and most prefer to go on living with the condition judged by the outsider as “worse than death”.’⁸⁶

81 J Greene, *Moral tribes*, 2015, p. 349.

82 J Greene, *Moral tribes* 2015, p. 15.

83 J Greene, 2015, p. 263–264.

84 S Sontag, *Regarding the pain of others*, 2003, p. 125–126.

85 H Carel, *Phenomenology of illness*, 2016, p. 135–136.

86 H Carel, *Phenomenology of Illness*, 2016, p. 139.

Despite or perhaps because of this inability to imagine, several art photographers have made works about their own illnesses trying to convey what it is like.

In conflict photography, art photographers have in general avoided the locus of the action and have instead concentrated on what has been left behind as the photography historian Charlotte Cotton writes:

‘Contemporary art photographers have, in the main, taken an anti-reportage stance: slowing down image making, remaining out of the hub of action, and arriving after the decisive moment. The use of medium and large format cameras (as opposed to 35 mm format) not normally seen at the sites of war and human disaster – not, at least since the mid-nineteenth century – has become a sign that a new breed of photographers is framing the social world in a measured and contemplative manner.’⁸⁷

An example of the approach Cotton describes is the French artist Luc Delahaye’s ongoing *History series*. The large panoramic images are almost two-and-a-half metres wide. One of them, *Kabul Road* (2001) shows a large group of men and boys posing for the camera on an empty road with dead bodies in the middle of the photograph. According to Cotton:

‘They make for shocking images, in part because his subjects [...] are so composed. The shock is also in the aesthetically seductive qualities of the prints.’⁸⁸

The photograph is beautiful and shows suffering, but it also shows that its beautifulness is deliberately constructed. In other words, Delahaye’s photograph leaves visible the fact that it is a construction of something instead of showing the beauty of the world as it is.

If contemporary art photographers have concentrated on the aftermath of conflicts and gone where the action has already stopped to make meaningful art, photographers portraying sickness, and especially illness, have found another way around the moral dilemma, and turned the cameras to their immediate family. As historian Charlotte Cotton writes, these intimate photography series are ‘rarely judged an outright failure because that would suggest a moral criticism of the photographer’s life, as well as of their motivations.’⁸⁹

Alan Radley and Susan E. Bell write that representations of illness are in the first place ideological, whether they are considered art or not. For them the main question is: ‘Who makes art about illness and for whom?’⁹⁰ The



Luc Delahaye: *Kabul Road*, 2001.

87 C Cotton, *The photograph as contemporary art*, third edition, Thames & Hudson Inc, New York, 2014, p. 167.

88 C Cotton, *The photograph as contemporary art*, 2014, p. 184.

89 C Cotton, *The photograph as contemporary art* 2014, p. 141.

90 S Bell, A Radley, ‘Another way of knowing: Art, disease and illness experience’, *Health* 15(3), 2011, p. 219.

researcher Anni Skilton states in the *Journal of Visual Communication of Medicine* that old medical photographs of patients should not be shown, especially in a commercial context:

‘it is of vital importance that they (and other images like them) are not used as material for entertainment purposes, or indeed for any purpose, which might affect the dignity of the subjects of these photographs.’⁹¹

Art historian W.J.T. Mitchell argues that the question of whether or not to show offensive or difficult images is more about context than content: ‘about where and when and to whom an image is displayed.’⁹²

If showing photographs of someone else’s suffering is morally questionable, showing one’s own suffering or family members’ suffering is acceptable, especially in the form of art therapy. Photographs of sick people are also acceptable when the photographs are used for example to enhance the doctor–patient relationship, with the artist serving as an intermediary, as in Deborah Padfield’s research,⁹³ or when photographs are used as photo-elicitation for example with brain injury patients as in Laura Lorenz’s research.⁹⁴

Another perspective on what representations of sickness do, is offered by anthropologists Arthur and Joan Kleinman. According to them representations of sickness define the very experience of sickness. Although the two authors concentrate mainly on media images in their article *The Dismay of Images*, they do offer viewpoints that add to the discussion at hand. The Kleinmans criticise images of suffering as global infotainment, as a commodity that is part of the political economy, because through this global market ‘experience is being remade, thinned out, and distorted.’⁹⁵

In other words, the Kleinmans underscore the fact that the representations of sickness and suffering do not just show the world but also create the world and the ways of being in the world. Arthur Kleinman, together with Veena Das and Margaret Locke (1997), make a demand for responsibility of representation:

91 A Skilton, ‘Recording the diseased and deceased: A historical look at medical illustration at 19th century Bristol’, *Journal of medical communication in medicine*, 38:1–2, p. 85–94, 2015, p. 93.
92 W J T Mitchell, *What do pictures want?*, 2005, p. 142.
93 D Padfield, “‘Representing’ the pain of others”, *Health* 15(3), 2011, p. 241–257.
94 L S Lorenz, ‘A Way into empathy: A “case” of photo-elicitation in illness research’, *Health* 15(3), 2011, p. 259–275.
95 A Kleinman, J Kleinman: ‘The dismay of images: Cultural appropriations of suffering in our times’ in *Social suffering*, A Kleinman, V Das & M Lock (eds.), Berkeley, Los Angeles, London, University of California Press, p 1.–25, 1997, p. 2.

‘What we represent and how we represent it prefigure what we will, or will not, do to intervene. What is not pictured is not real. Much of routinized misery is invisible, much that is made visible is not ordinary or routine. The very act of picturing distorts social experience in the popular media and in the profession under the impress of ideology and political economy. So entailed, even personal “witnessing” is compromised.’⁹⁶

For Arthur Kleinman there are cultural constructions defining the ‘right’ way of being ill and the ‘wrong’ way. Sociologist Deborah Lupton writes that in Western societies good patients are expected to be optimistic, strong, happy and die brave; ‘cowardice, giving in, fear and “denial” are not considered socially acceptable ways of dealing with disease’.⁹⁷

Representations of ill people negotiate and modify this distinction of right and wrong ways of being ill and being a patient. This is also the area that British artist Jo Spence wanted to infiltrate with her work *The Picture of Health?*, in which she questions and criticises the representations of a patient as a passive object.

Sander L. Gilman has traced the way patients and the diseased are understood and represented as basic stereotypes:

‘It is this fantasy of wholeness, which lies at the root of all of the bipolar images of difference (health vs. disease; good vs. bad, white vs. black) which comprise our construction of all stereotypes, including those of health and disease.’⁹⁸

Again, it is good to be reminded that images themselves don’t do anything, people do. Susan Sontag writes that the meaning of the photograph ‘will have its own career blown by the whims and loyalties of the diverse communities that have use for it.’⁹⁹ Photographs are used by different groups of people for different motives and political purposes.

One example is the case of Therese Frare’s photograph of David Kirby, shown as he was a patient dying of AIDS. The photograph caused an outrage when it was commercialised. In the photograph, Kirby, surrounded by his family, lies dying from AIDS in a hospital bed in 1990. The photograph was published in *LIFE* and also won the World Press Photo award. Two years after the photograph was taken, the Italian clothing company Benetton used a colour version of the photograph in an AIDS campaign, which aroused widespread outrage. A high-profile AIDS charity

96 A Kleinman, V Das & M Lock (eds.), *Social suffering*, 1997, p. xiii.
97 D Lupton, *Medicine as culture*, 2003, p. 72.
98 S L Gilman, *Disease and representation*, 1988, p. 5.
99 S Sontag, *Regarding the pain of others*, 2003, p. 39.

wanted to ban the ad, because they found it offensive and unethical. *Elle*, *Vogue* and *Marie Claire* refused to run the ad, and for example, London's *Sunday Times* condemned the use of the photo.¹⁰⁰ The cultural critic Henry A. Giroux sees Benetton's campaign as exploitation:

'Benetton did more than conjoin the worlds of beauty and suffering; it also pushed a mode of commercial advertising in which the subjects of often horrendous misfortunes and acts of suffering disappeared into the all-embracing world of logos and brand names.'¹⁰¹

However, Kirby's parents were not upset in any way. They later said in an interview: 'David is speaking much louder now that he's dead, than he did when he was alive.'¹⁰² According to *Time Magazine* journalist Ben Cosgrove:

'Frare's photograph went a long way toward dispelling some of the fear and, at times, willful ignorance that had accompanied any mention of the disease.'¹⁰³

To sum up the different approaches and moral claims about exhibiting or not exhibiting photographs of suffering and sickness in an art context, I have drafted it as follows:

1. *Authentic suffering: art photographs representing actually sick or tortured people*

Showing these images in an art context is morally controversial. It is ok to show the photograph, if the photograph says 'Stop this!' or 'Never again!'; in other words raises critical awareness aimed to change the current situation. Nevertheless, if the photographs are just visually appealing spectacles and do not invite critical reflection, it is troublesome to show the images. The difficult part is defining what the images say. Also, there is at least one extenuating circumstance: that the photographer is the sufferer or a close relative of the sufferer.

2. *Constructed suffering; photographs representing staged scenes or events of suffering*

100 B Cosgrove, 'Behind the picture that changed the face of AIDS', *Time Magazine*, Nov 25, 2014, accessed April 23, 2016, www.time.com/3503000/behind-the-picture-the-photo-that-changed-the-face-of-aids/
101 H A Giroux, 'Disturbing pleasures', *Third Text*, 26:3, p. 259–273, 2012, p. 261.
102 *The Guardian*, 'Benetton's most controversial adverts', Nov 17, 2011, accessed April 23, 2016, <http://www.theguardian.com/fashion/gallery/2011/nov/17/benettons-most-controversial-adverts>
103 B Cosgrove, *Time Magazine*, 2014.

These images are not only okay to show in an art context but also praised, for example by Sontag, as powerful anti-war images. The crucial point of this category is that the viewer knows whether the scene is real or not. This applies to the very first art photograph of sickness, *Fading Away* by Henry Peach Robinson. The completely staged composite image depicts a young woman dying of tuberculosis. According to Robinson himself, the photograph would have been too horrible to look at if it were real.¹⁰⁴ That is also what some of his contemporaries thought too, as they believed the photograph to be a depiction of real events.

Luc Delahaye's *History series* lands in between the two categories. The people and their suffering are real, but the scene is constructed. And it is the construction that leads Charlotte Cotton to admire the image.

Mark Reinhardt states in the book *Beautiful Suffering* that even photos which are critical of suffering cannot help but to show the actual suffering. Reinhardt doubts if one can ever criticise using the same type of images one wants to criticise.¹⁰⁵ In other words, no matter how one would show critical images of suffering, there is still suffering in them. Reinhardt however operates on a reality level, taking for granted that the suffering is real. Constructed images of suffering can indeed criticise how the real suffering is depicted and still use the same visual language.

This categorisation above is a very general one and mainly applies to art photographs depicting people. Different criteria could apply to machines, scenes and objects that are related to suffering.

2.2. Disturbing images

Another question that derives from the previous research on representations of sickness is: *Why is it so uncomfortable to look at photographs of sickness and suffering?*

The next part of the chapter looks into why people sometimes feel disgusted (and fascinated) when looking at art photographs depicting diseases

The majority of researchers who have written about the portrayal of sickness or harrowing images seem to agree that looking at photographs of sickness, death, dismembered body parts or diseases is disturbing.

104 D L Coleman, *Pleasant fictions: Henry Peach Robinson's composition photography*, The University of Texas at Austin, 2005, p. 126.
105 Reinhardt et al., *Beautiful suffering*, 2006, p. 10.

Social scientist Alan Radley states that the images of suffering and surgical disfigurement make the viewer look away from the image because of ‘formless fears and anxiety that the image opens up’.¹⁰⁶

Researcher Mary O’Neill goes further than Radley in her research, claiming that some images of the dead bother people because the viewers actually feel their own and their loved one’s mortality. In her article *Speaking to the Dead*, she backs up the claim with psychological and neuro-scientific research. She refers to Keysers et al., who found that seeing a tarantula move on a person’s chest activates the same brain circuit as actually being touched by a spider.¹⁰⁷ In other words, when we see someone being touched, we might instantly feel a similar kind of touch ourselves without having to first think about how it might feel. O’Neill concludes that what makes photographs of dead people problematic is not the images themselves or the actual dead in them, but the emotions and feelings of our own coming death that the images evoke.¹⁰⁸ Art historian Suzannah Biernoff comes to a similar conclusion as O’Neill and Radley in her article *Medical Archives and Digital Culture*. She writes that ‘photographs of suffering somehow contain or embody their subjects; and that they therefore carry a burden of care’.¹⁰⁹

For cultural and literary historian Sander L. Gilman, representations of the diseased are never benign:

‘Thus an inherent tension exists between the world of art representing disorder, disease, and madness and the source of our anxiety about self-control. This tension provides the ambiguity inherent in the creation and reception of images of disease.’¹¹⁰

He notes that how we see the sick and the patient are socially coded. Gilman continues: ‘How we see the diseased, the mad, the polluting is a reflex of our own sense of control and the limits inherent in that sense of control.’¹¹¹

However, the difficulty of looking at harrowing photographs is deeply entwined with a fascination to look at them. Psychoanalyst Julia Kristeva reminds us that people have always been eager to see gruesome sights:

106 A Radley, *Works of illness: Narrative, picturing, and the social response to serious disease*, InkerMen Press, Ashby-de-la-Zouch, 2009, p. 6.
107 C Keysers, B Wicker, V Gazzola, J L Anton, L Fogassi and V Gallese, ‘A touching sight: SII/PV activation during the observation and experience of touch’, *Neuron* 42(2), p. 335–346, 2004, p. 335.
108 M O’Neill, ‘Speaking to the dead: Images of the dead in contemporary art’, *Health* 15(3), p. 299–312, 2011, p. 299.
109 S Biernoff, ‘Medical archives and digital culture’, *Photographies* 5:2, 2012, p. 198.
110 S L Gilman, *Disease and representation*, 1988, p. 2–3.
111 S L Gilman, *Disease and representation*, 1988, p. 3.

‘Not to mention those countless anonymous voyeurs, across the ages, who have been fascinated by victims of the guillotine, the electric chair, fatal chemical injections, televised criminal trials, those put to death in film clip. [...] The technology changes; voyeurism itself never ceases to paint, sculpt, photograph.’¹¹²

Likewise, Susan Sontag reminds us that repulsive images also allure: ‘Everyone knows that what slows down highway traffic going past a horrendous car crash is not only curiosity.’¹¹³ In *On Photography*, Sontag explains the interest in horrible photographs by the fact that they happen to someone else, somewhere else, and the viewer herself or himself is exempt from the horrible. According to Sontag, western society has brushed away misery, pain and death, and this in turn creates a curiosity for them, which in turn can be satisfied by taking photographs.¹¹⁴ Sontag acknowledges that already Plato was aware of the attraction to the horrible, and offers that looking at horrible photographs can also serve a need: ‘To steel oneself against weakness. To make oneself more numb. To acknowledge the existence of the incorrigible.’¹¹⁵

It can also be a way to learn. Israeli scholar and teacher Ya’ara Gil-Glazer showed disturbing photographs of violence, suffering and extreme sexuality to 14 pedagogy students and interviewed them about their reactions to the images. The images included among others Nick Ut’s *Children fleeing an American napalm strike* in 1972. Gil-Glazer writes that the students’ reactions:

‘indicate a complex yet clear attitude of rejection-attraction. In other words, such photographs are perceived as threatening and intriguing at the same time [...]’¹¹⁶

Gil-Glazer notes that photographs depicting difficult subject matters are essential to education because they trigger critical discussion on society as a whole, and that this kind of photography may, instead of just arousing objection and denial, lead to critical, educational thoughts.¹¹⁷ In other words, the students learn to encounter their own feelings, examine the photographic rhetoric and read photographs in a critical manner.

112 J Kristeva, *The severed head. Capital visions*, New York, Columbia University Press, 2014, p. 107.
113 S Sontag, *Regarding the pain of others*, 2003, p. 95.
114 S Sontag, *On photography*, 2011, p. 168.
115 S Sontag, *Regarding the pain of others*, 2003, p. 98.
116 Y Gil-Glazer, ‘Photography, critical pedagogy, and “difficult knowledge”’, *The International journal of education through art* Vol. 11(2), p. 261–276, 2015, p. 268.
117 Y Gil-Glazer, *The international journal of education through art*, 2015, p. 274–275.

This combination of disgust and fascination with looking at photographs of sickness will be addressed more in detail in Chapter Five where I scrutinise photographic works in relation to the concept of abject. The same chapter introduces the theoretical formations of which I am taking advantage in the quest to understand how sickness has been represented in art photography.

Next, in Chapter Three, I look at the definitions of sickness and trace how sickness and art photography have historically intertwined, and what kind of works have been done on the topic.

3.

Sickness and Art Photography

The first part of this chapter looks into definitions of sickness in the context of this research and the second examines how photography and sickness have intertwined since photography's invention. The third part examines Henry Peach Robinson's *Fading Away*, Jo Spence's various works and Raphaël Dallaporta's *Fragile*. The chapter ends with a diagram that maps 67 art photography works in relation to Arthur Kleinman's definitions of sickness, illness and disease.

3.1. Defining sickness

The dictionary definitions of sickness describe it as an illness. In the Merriam-Webster dictionary sickness defined as 'ill health, illness or a disordered, weakened, or unsound condition', and in Oxford dictionary sickness is 'the state of being ill'. The same dictionaries describe illness as 'sickness or an unhealthy condition of body or mind' or as 'a disease or a period of sickness affecting the body or mind'. Disease in turn has a naturalistic definition in both dictionaries: 'a condition of the living animal or plant body or of one of its parts that impairs normal functioning and is typically manifested by distinguishing signs and symptoms'.¹¹⁸

The medical historian Henry E. Sigerist writes that disease as a phenomenon is as old as life itself: 'Because disease is nothing else but life, life under changed circumstances as Virchow defined it'.¹¹⁹ On a very basic level, sickness is defined in relation to life and death, and life and death have various definitions. The Merriam-Webster defines life as: 'The period of time when a person is alive. / The experience of being alive'.¹²⁰ The problem is that scientists and philosophers do not agree on the definitions of life and death in principle, not even when it is about human life or death. According to the philosopher Eugene Thacker, the question of life defines our era:

'If the question of Being was the central issue for antiquity (resurrected in the twentieth century by Heidegger), and if the question of God, as alive or dead, was the central issue for modernity (Kierkegaard, Marx, Nietzsche), then perhaps the question of 'life' is the question that has come to define our contemporary era [...]'¹²¹

118 Merriam-Webster online dictionary, accessed Sep 20, 2017, www.merriam-webster.com/dictionary/sickness, /illness, and /disease. And Oxford Living Dictionary, accessed Sep 20, 2017, en.oxforddictionaries.com/definition/sickness, /illness and /disease.

119 Henry E. Sigerist, *A history of medicine, Volume 1, Primitive and archaic medicine*, Oxford University Press, New York and Oxford, 1987, p. 38.

120 Merriam-Webster online dictionary, accessed Dec 29, 2015, www.merriam-webster.com/dictionary/life

121 E Thacker, *After life*, The University of Chicago Press, Chicago and London, 2010, p xiii.

Biologists have not yet decided if viruses are alive or not – whether or not it is sufficient that they have their own genetic material, even though they are dependent upon another organism to replicate. Looking more broadly, humans also need other organisms (as food) to grow and replicate. A post-humanist perspective, introduced by Cary Wolfe, would be to look at humans as just one life form among many.¹²² Thacker argues though that if life is defined as an experience of living 'this also means that life becomes a human centric concern. Life in this sense really means life-for-me, or life-for-us'.¹²³ My research likewise takes a human point of view, because sickness is usually seen as a concern only when it appears in humans. When animals or plants get sick, it is often seen (by humans) as the normal course of nature.

Similarly, just as the definitions of life are hazy, so are those of death. How to define human death is a scientific and philosophical question, and the answer depends on what constitutes a human: the whole organism or just the brain. How many organs or brain functions must stop working before a human is dead and at what point do we know that something is irreversibly lost? According to the now-prominent whole-brain approach, a person dies when the entire brain, including the brainstem, is irreversibly lost, whereas the higher-brain approach draws the line at the moment when the 'capacity for consciousness' is irreversibly lost, and third approach states that when the cardiopulmonary function is irreversibly lost a person is dead.¹²⁴

All these approaches have their own problems: is a person in a vegetative state alive or is a late stage Alzheimer's patient conscious? This is not only a philosophical debate regarding what constitutes a human, but a medical, political and economic question: when can organs be harvested and when can someone be taken off life support?¹²⁵ For example Finland was among the first countries in the world, in 1971, to accept brain death as a legal definition of death, which in turn allowed the heart to be harvested for transplant surgery.¹²⁶ By contrast, in Japan, when a patient has been clinically proven brain-dead, relatives are empowered to make the final decision as to whether this counts as death.¹²⁷ The case of death is even more complicated when it comes to organ transplantation, where the

122 C Wolfe, *What is posthumanism?*, University of Minnesota Press, Minneapolis, 2010.

123 E Thacker, *After life*, 2010, p. 27, 29.

124 D DeGrazia, 'The Definition of Death', *The stanford encyclopedia of philosophy*, Fall 2011 Edition, E N Zalta (ed.), accessed Dec 29, 2015, plato.stanford.edu/archives/fall2011/entries/death-definition

125 D DeGrazia, 'The definition of death', *The stanford encyclopedia of philosophy*, 2011.

126 D Price, *Legal and ethical aspects of organ transplantation*, De Montfort University, Cambridge University press, Leicester, 2000, p. 55.

127 A Bagheri, 'Individual choice in the definition of death', *J Med Ethics*, Mar; 33(3), p. 146–149, 2007. Also Japan Organ Transplant Network, accessed Jan 21, 2017, <https://www.jotnw.or.jp/english/>

existence of a “living cadaver” [...] created by an accident and sustained by medical technology’ is possible.¹²⁸

Definitions of sickness, and disease and illness, have varied over the decades and centuries, and they are still debated and negotiated. Despite the fact that the concept of disease has changed, the medical historian Henry E. Sigerist points out that there has always been a trend to remove the cause of the disease, whether the cause has been

‘a possession by an evil sprit, punishment for sin by the benevolent deity, a disturbance in the balance of hypothetical humors, or atoms, or in the balance of physical and chemical forces.’¹²⁹

In ancient Greece, Hippocrates proposed that a healthy human body has a balance of four bodily fluids, or humors: black bile, yellow bile, phlegm and blood. An imbalance of these liquids would cause disease.

In the 1600s, diseases were generally seen as God’s punishment.¹³⁰ In the 1700s, patients were seen as scientific riddles to be solved in the West.¹³¹ In the 1800s, according to Foucault, French anatomist Marie François Xavier Bichat introduced death into the concept of disease: ‘It is not because he falls ill that man dies; fundamentally, it is because he may die that man may fall ill.’¹³²

In the same tone Bichat defined life as ‘the ensemble of functions which resist death.’¹³³ Foucault describes this life/disease/death relationship also as ‘Death is disease made possible in life.’¹³⁴ In his book, *History of Madness*, published in the 1960s, Foucault defined sickness as a cultural, legal, political, historical and medical construct, specific to each historical era.

Most commonly, sickness has been seen as something that opposes health. World Health Organization defined health in 1948 as ‘a state of complete physical, mental and social wellbeing not merely the absence of disease or infirmity’.¹³⁵ WHO has not since revised this definition.

128 M Lock, *Twice dead. Organ transplants and the reinvention of death*, University of California Press, Berkeley, Los Angeles, London, 2002, p. 1.
129 H E. Sigerist, *A history of medicine, Volume 1*, 1987, p. 10.
130 M Foucault, *History of madness*, Routledge, London and New York, 2006, p. 86.
131 M Foucault, *The birth of the clinic: An archaeology of medical perception*, Vintage Books, New York, 1994, p. 59.
132 Foucault, *The birth of the clinic*, p. 146.
133 S Sontag, *Illness as metaphor and AIDS and its metaphors*, Doubleday, New York, 1991, p. 74.
134 M Foucault, *The birth of the clinic*, p. 156.
135 Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19–22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948, accessed Dec 20, 2015, www.who.int/governance/eb/who_constitution_en.pdf

Sociologists, on the other hand, have been active in reconstructing and analysing health, and in mapping the relation of health and sickness. The sociologist Jürgen Pelikan makes his definition as such that:

‘the amount of total health of a living system is its amount of positive health minus its amount of illness [...] So, logically, it would be more correct to speak of illness “of” or “within” health, than of illness “and” health. (Metaphorically, we could understand the relationship of the two as one of host and parasite.)’¹³⁶

In the philosophy of medicine, defining ‘health’ and ‘disease’ is still unsettled.¹³⁷ Next, I will briefly introduce the latest philosophical views on the definitions of disease and then move to the anthropological definitions, which give this research its main structure.

In philosophical discussions, naturalist and constructivist views on disease are frequently presented. A third point of view is offered by phenomenologists, who emphasise the experience of being healthy or ill. A naturalist scholar takes as a fact that there is a standard functioning human body and that a disease is an abnormal process that is unbeneficial for a human body, whereas a constructivist looks at cultural values and practices first, and then looks for a biological process to blame for it.¹³⁸ In other words:

‘for naturalists, diseases are objectively malfunctioning biological processes that cause harms. For a constructivist, diseases are harms that we blame on some biological process because it causes the harm, not because it is objectively dysfunctional.’¹³⁹

Constructivists often use examples like alcoholism and obesity. Researchers have linked obesity to high blood pressure and a shorter life expectancy. However, according to the constructivist view, the reason why scientists looked for these links to begin with, was an existing cultural belief that fat people are something morally and aesthetically disgusting, and therefore finding a medical justification would excuse this discrimination.¹⁴⁰ There are many constructivists examples: in the 1800s

136 J M Pelikan, ‘Understanding differentiation of health in late modernity by use of sociological systems theory’, *Health and modernity: the role of theory in health Promotion*, D V McQueen, I Kickbusch, L Potvin, J M Pelikan, L Balbo, Th Abel (eds.), Springer Science+Business Media LLC, New York, 2007, p. 78.
137 M Lemoine, ‘Defining disease beyond conceptual analysis: an analysis of conceptual analysis in philosophy of medicine’, *Theoretical medicine and bioethics*, 34:309–325, 2013, p. 309.
138 D Murphy, ‘Concepts of disease and health’, *The Stanford encyclopedia of philosophy*, Spring 2015 Edition, E N Zalta (ed.), accessed May 20, 2015, plato.stanford.edu/archives/spr2015/entries/health-disease/, p. 5.
139 Murphy, *The Stanford encyclopedia of philosophy*, 2015.
140 Murphy, *The Stanford encyclopedia of philosophy*, 2015, p. 8.

American slaves ran away due to a disease called drapetomania, and until the 1970s many psychiatrists thought that homosexuality was a mental illness.¹⁴¹ Historian Sander L. Gilman, who has written extensively about the history of medicine, traced how for example syphilis has been culturally represented: ‘The dichotomy between the beautiful and the ugly seem to be inherent in all of the cultural constructs of health and disease in the nineteenth and twentieth centuries.’¹⁴²

Despite the multitude of constructivist examples, the naturalist view dominates contemporary medicine.¹⁴³ According to this view, functional processes and standards for an average human being exist on their own, regardless of what people think of them. For naturalists, there is a statistical normality, a species design of how an ideal physical human operates.¹⁴⁴ However, statistical reasoning in defining a disease has its problems when it is about aging for example; dental caries and atherosclerosis are statistical norms when it comes to the elderly, but they are still considered diseases.¹⁴⁵ Taken to the most extreme, dying is considered a biological dysfunction although a statistic given. Dominic Murphy, a philosopher of the cognitive and biological sciences, criticises the certainty in the naturalist theory:

‘[I]n the life sciences, some biological system can fail to behave as a theory predicts without impugning the prediction: we can say that the system is malfunctioning. This contrasts with other sciences, in which, if a system fails to behave as predicted, the fault lies with the science, not the system.’¹⁴⁶

Another criticism against the naturalist theory comes from phenomenology. The philosopher Havi Carel writes that the naturalistic view cannot in principle capture illness, because it only sees people as biological units and reduces patients’ bodies to mere objects. Carel, following Merleau-Ponty, makes the distinction between the biological body and the lived body. She writes that the phenomenological view on sickness also takes into account ‘the ill person’s relationship to her social and physical world.’¹⁴⁷ Carel stresses that people are inseparable mental-bodily units; our consciousness is not separate from our body and that is why nothing is ever only biological.¹⁴⁸

The phenomenological approach to sickness emphasises being in the world, the experience of being ill. Carel states: ‘On this view, the experience of any particular individual will be influenced by, and in constant dialog with others’ experiences.’¹⁴⁹ She notes that, for medical services, the effects an illness has on the patient’s life are largely ignored, as the aim is to cure the material disease.¹⁵⁰ However, according to Murphy, the phenomenological perspective in turn seems to be largely ignored in contemporary medicine, but applied in disability studies.¹⁵¹

One of the most influential writers in the analytic philosophy of medicine, Christopher Boorse, differentiates between disease and illness in his article *Health as a Theoretical Concept* (1977). For him disease is a deviation of the species-typical design and illness is the judgment that this disease is unwanted or harmful. For example, colour-blindness is a deviation from the normal colour sight and considered a disease, but colour-blind people do not consider themselves ill.¹⁵² Boorse’s views are largely used especially in medicine but also debated.¹⁵³ For example, Havi Carel criticises Boorse’s view because it splits human experience into two instead of understanding people as one unified entity.¹⁵⁴

For anthropologists and sociologists, the naturalistic and constructivist definitions introduced above were too abstract, and a desire to look at health and illness in a cultural and social context peaked in anthropology in the mid-1980s.¹⁵⁵ A few years after Boorse’s article, in the early 1980s, the anthropologist Arthur Kleinman started developing a version of the disease/illness differentiation, later also adding one more distinction: sickness. Kleinman revised his own definitions of illness and disease in 1983 to follow the ones developed by his fellow anthropologist Robert Hahn, who had criticised Kleinman and others for taking the biomedical view on disease as an ontological truth.¹⁵⁶ Kleinman clarified his standpoint:

‘When we fall sick we (including physicians themselves) first experience illness. This is the culturally constituted, socially learned response to symptoms that includes the way we perceive, think about, express and cope with sickness. Illness is embedded in everyday idioms

141 Murphy, *The Stanford encyclopedia of philosophy*, 2015.

142 S L Gilman, *Health and illness, images of difference*, Reaktion Books, 1995, p. 54.

143 Murphy, *The Stanford encyclopedia of philosophy*, 2015, p. 8.

144 C Boorse, ‘Health as a theoretical concept’, *Philosophy of science*, 44: 542–573, 1977, p. 542.

145 Boorse, *Philosophy of science*, 1977, p. 566.

146 Murphy, *The Stanford encyclopedia of philosophy*, 2015, p. 22.

147 H Carel, ‘Can I be ill and happy?’ *Philosophia* 35(2): 95–110, 2007, p. 95.

148 H Carel, *Philosophia*, 2007, p. 99–100.

149 H Carel, ‘Phenomenology as a resource for patients’, *Journal of medicine and philosophy*, 37: 96–113, 2012, p. 100.

150 H Carel, *Journal of medicine and philosophy*, 2012, p. 97–98.

151 D Murphy, *The Stanford encyclopedia of philosophy*, 2015.

152 Boorse, *Philosophy of science*, 1977, p. 551–552.

153 J C Wakefield, ‘The Biostatistical theory versus the harmful dysfunction analysis, part 1: Is part-dysfunction a sufficient condition for medical disorder?’, *Journal of medicine and philosophy*, Dec;39(6), 2014, p. 648–82.

154 H Carel, ‘Can I be ill and happy?’, *Philosophia* 35(2): 95–110, 2007, p. 100.

155 A Young, ‘The anthropologies of illness and sickness’, *Annual review of anthropology*, Vol. 11, 1982, p. 257–258.

156 R A Hahn, ‘Rethinking “illness” and “disease”’, *Contributions to asian studies*, vol XVIII, Jan 1:1, 1984, p. 1–23.

and life ways that are more or less understandable to members of the same culture and life world. When the sick person first visits a practitioner, the two initially communicate in terms of culturally shared illness idioms. But soon thereafter the practitioner begins to further construct the sickness in the technical terms of his theoretical system, be it biomedicine, psychoanalysis, chiropractic, or traditional Chinese medicine, for example. This technical reconstruction constitutes disease.”¹⁵⁷

Hahn had also placed illness, disease and disorder under a larger umbrella of suffering, which Kleinman also adopted. I will first introduce Kleinman and his views on suffering and biomedicine, and then move to his definitions of sickness, illness and disease.

Arthur Kleinman (b. 1941) is a psychiatrist and anthropologist, who is best known for his books in the field of medical anthropology: *Patients and healers in the context of culture* (1980) and *The Illness Narratives: suffering, healing, and the human condition* (1988). For Kleinman, sickness cannot be separated from social and political conditions, as he places sickness under a larger umbrella of social suffering. According to Kleinman social suffering entails ‘every different kind of human problem that creates pain, distress, and other trials for people to undergo and endure.’¹⁵⁸ Thus the more crucial point is that:

‘social suffering results from what political, economic, and institutional power does to people and, reciprocally, from how these forms of power themselves influence responses to social problems.’¹⁵⁹

As an example of social suffering, Kleinman uses atrocity and poverty, both of which produce ill health and death but are also political issues. He steers the attention of sickness away from an individual person who just happened to fall ill to the structures, policy makers and medical institutions.

Kleinman stresses that institutionalised forms of medicine, especially biomedicine, are part of social control and power structures.

‘No other therapeutic system can exercise this degree of power, because no other has become so powerful a part of the state’s mechanisms of social control.’¹⁶⁰

By this he means that when researchers and doctors define what a particular sickness is and how it should be treated, it affects legislation more than the actions of those in many other professions. It also enables

157 A Kleinman, Editor’s note, *Culture, Medicine and psychiatry* 7, 1983, p. 97–99.

158 Kleinman, *Writing at the margin*, 1997, p. 13.

159 Kleinman A, Das V, Lock M (eds.), *Social suffering*, 1997, p. ix.

160 Kleinman, *Writing at the margin*, 1997, p. 38.

diminished responsibility, for example when victims of torture are defined as patients with post-traumatic stress disorder. According to Kleinman:

‘Vietnam veterans with PTSD are not so much victims of a mental disorder as they are victims of (and victimizers through) the political decisions of their nation’s leaders.’¹⁶¹

Kleinman takes a critical standpoint to the claim that technological innovations and pharmaceuticals are developed in response to human needs: why should for example menopause be defined as a disease? According to him, especially in North America, the focus is on controlling and biomedically repairing individual bodies instead of focusing on the origins of the (social) suffering.¹⁶² Likewise the sociologist Jürgen Pelikan highlights that it is clinical medicine that has developed into a powerful system that has a monopoly over the human body, despite the fact that public health is a more efficient means to prevent infectious diseases or to increase life expectancy than clinical medicine.¹⁶³ For example it has been proven that increasing awareness about the harms of smoking, and changing people’s behaviour through the ban of indoor smoking, reduces lung cancer with greater success than any clinical treatment.

Even more drastically it can be seen that medicine maintains the status quo by directing attention to individuals and treating their symptoms and visible signs of illness instead of looking at the causes of ill health as structural phenomena.

‘[P]atients suffering from stress or depression are routinely counselled to alter their lifestyle by taking up jogging or meditation, or are prescribed mood-altering drugs, strategies which tend to direct attention away from the socio-economic factors causing the condition.’¹⁶⁴

In addition, clinical medicine has expanded beyond the borders of treating only disease into addressing other aspects of human biology such as fertility, physical looks, aging, dying, fitness abilities, and even social behaviours. Pelikan summarises this expansion as ‘medicalization of life’.¹⁶⁵ Researcher Margaret Lock states: ‘biomedicine, has come to be thought of by many as one form of neo-imperialism.’¹⁶⁶

161 Kleinman, *Writing at the margin*, 1997, p. 44.

162 Kleinman, *The illness narratives*, 1988.

163 Pelikan, *Health and modernity*, 2007, p. 93–94.

164 D Lupton, *Medicine as culture*, 2003, p. 116.

165 Pelikan, *Health and modernity*, 2007, p. 96.

166 M Lock, ‘Displacing suffering: The reconstruction of death in North America and Japan’, in *Social suffering*, A Kleinman, V Das, M Lock (eds.), University of California Press, Berkeley, Los Angeles, London, p. 207–245, 1997, p. 211.

Kleinman’s concept of social suffering reminds us that the representations of suffering are anything but objective. He outlines, together with Veena Das and Margaret Lock, how representations of suffering are at the same time spectacles and representations of the ‘real’. However, in their view what is represented is the ‘real’ of those in power.¹⁶⁷ In other words, representations of suffering not only construct reality, but they also become it. ‘How we “picture” social suffering becomes that experience, for the observers and even for the sufferers/perpetrators.’¹⁶⁸ Ultimately, representations of illness dictate (but also negotiate) the very experience of being ill.

3.2. Kleinman’s sickness, illness and disease

Arthur Kleinman differentiates between sickness, disease and illness in his book *The Illness Narratives* (1988). Kleinman combines both the physical and the cultural world in his definitions. In contrast to Boorse’s definitions Kleinman’s emphasise the subjective, lived illness experience to a greater degree.

In general, Kleinman’s definitions can be considered more practice-based than philosophical, as the main aim of his book was to provide better understanding of and better care for chronically ill patients. Kleinman criticises the way medical students are taught that:

‘symptoms are clues to disease, evidence of a "natural" process, a physical entity to be discovered or uncovered. They are rarely taught that biological processes are known only through socially constructed categories that constrain experience as much as does disordered physiology [...]’¹⁶⁹

In other words, Kleinman wishes to highlight that ‘both symptoms (complaints) and signs (observable indications) of disease are in fact interpretations.’¹⁷⁰

Kleinman is not the only anthropologist emphasising this. Allan Young writes that Good (1977) and Frake (1961) both stress that illness is

constructed in semantic networks of meaning that refer to language, situations, and to the experience of being ill, which in turn also makes clinical practice interpretative.¹⁷¹

For Kleinman sickness entails context, political, economic and institutional power structures. Sickness is the blanket term that combines both the biomedical model (disease) and the experience given in the sociocultural context of the patient (illness). Disease is the way medical practitioners and biologists look at sickness as a biological dysfunction. Kleinman stresses that the biomedical model, disease, pressures doctors and practitioners to make the biological dysfunction the centre of the treatment and disregard everything else as invalid subjective information. The result being that what gets disregarded is:

‘the experience of bearing and enduring pain as a coming to terms with that which is most at stake, that which is of ultimate meaning, in living [...]’¹⁷²

Illness is the way disease is experienced. It comprises all the ways that ‘the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability.’¹⁷³ Kleinman emphasises how the lived experience of being ill, is tightly entwined with cultural, historical and social structures, for example in medical science and practice there is a normal and abnormal way of being ill. In short, for Kleinman, disease is what we medically have, illness is how we experience it, and sickness is the way, for example, how our government addresses it.

Deborah Lupton writes that medical anthropologists are sometimes criticised for their practical aims to develop better means for doctors and hereby support the hegemonic ideologies.¹⁷⁴ The onset of Kleinman’s analysis was indeed to enhance the clinical experience and to try to provide better care. However, Kleinman takes a much more culturally critical standpoint with his writings on social suffering. Despite Kleinman’s writing on social suffering, Allan Young criticises Kleinman for not applying the definition model of illness and disease in Kleinman’s own analysis; according to Young, although Kleinman writes about social relations shaping sickness, he looks at sickness from the individual’s point of view and starts from the clinical experience outwards¹⁷⁵.

The disease–illness dichotomy used by medical anthropologists has been criticised for its reinforcement of body–mind distinction, (objective–subjective), where the body has the disease, which is real and can be

167 A Kleinman, V Das, M Lock (eds.), *Social suffering*, 1997, p. xii.
168 A Kleinman, J Kleinman, ‘The appeal of experience; The dismay of images: Cultural appropriations of suffering in our times’ in *Social suffering*, A Kleinman, V Das, M Lock (eds.), University of California Press, Berkeley, Los Angeles, London, p. 1–25, 1997, p. 2.
169 Kleinman Arthur, *The illness narratives: Suffering, healing and the human condition*, Basic Books, New York, 1988, p. 17.
170 A Kleinman, *Writing at the margin*, 1997, p. 73.

171 A Young, *Annual review of anthropology*, 1982, p. 262–263.
172 Kleinman, *Writing at the margin*, 1997, p. 32.
173 Kleinman, *The illness narratives*, 1988, p. 3.
174 D Lupton, *Medicine as culture*, 2003, p. 15.
175 Young, *Annual review of anthropology*, 1982, p. 269.

measured, whereas the mind has the illness, which is subjective and ambivalent and therefore its realness can be questioned.¹⁷⁶ However, Kleinman's disease, which is an interpretation in a medical context, is not an objective 'truth', and his illness is culturally constructed, shared and experienced, rather than just a subjective experience. Kleinman's definitions draw attention to two distinctly constructed ways of understanding sickness in society.

In addition, Kleinman's definitions can be seen to overemphasise the medical point of view of sickness as illness is seen as just one of the three. According to Lupton, the medical view on sickness in general is dominant in Western culture. However, in the 2000s, there was particular interest in illness narratives in social sciences and medicine. According to sociologist Mike Bury this interest can be traced back to the anthropological distinction of disease and illness in the 1970s, but more importantly to the still accelerating separation of the medical model of disease and the lay experience of illness.¹⁷⁷ The more medical procedures and treatments develop the less the patient's subjective experience of the disease is important in a medical setting, and this in turn, together with the emergence of chronic illnesses, has brought the illness narratives into academic focus. Kleinman's definitions are still significant especially in the fields of medical ethics, narrative medicine and philosophy of medicine (for example Toombs, 2001).¹⁷⁸ It may even be that Kleinman's impact is more prominent in these domains than in the current discussions in medical anthropology. Especially the current growing interest in empathy studies has made Kleinman's thoughts timely.¹⁷⁹

While acknowledging the criticism of Kleinman's definitions, I have chosen to use them in my research, because they offer an analytic and clearly structured contextual perspective to look at different representations of sickness in art photography. They offer an analytic tool to examine the representations of sickness in a new way that includes the experience of being ill, the statistical disease and the politics and power structures of sickness and defining sickness. At the end of this chapter, I apply Kleinman's definitions to artworks, but before that I briefly trace how photography and sickness have been entangled since the 1850s.

176 R A Hahn, 'Rethinking "illness" and "disease"', *Contributions to asian studies*, vol XVIII, Leiden 18, Jan 1:1, p. 1–23, 1984, p. 2.
177 M Bury, 'Illness narratives: fact of fiction?', *Sociology of health & illness*, Vol. 23, no.3, p. 263–285, 2001, p. 263–6.
178 K Toombs, 'The role of empathy in clinical practice', *Journal of consciousness studies*, 2001:8, p. 5–7.
179 J Halpern, *From detached concern to empathy. Humanizing medical practice*, Oxford University Press, Oxford 2011. Also J Halpern, 'From idealized clinical empathy to empathic communication in medical care', *Medicine, health care and philosophy* 17: 301–311, 2014.

3.3. History of sickness and (art) photography

'Photography is haunted by two chattering ghosts: that of bourgeois science and that of bourgeois art. The first goes on about the truth of appearances, about the world reduced to a positive ensemble of facts, to a constellation of knowable and possessable objects. The second specter has the historical mission of apologizing for and redeeming the atrocities committed by the subservient – and more than spectral – hand of science', Allan Sekula writes.¹⁸⁰

Historical photographs representing sickness and especially the sick carry the baggage Sekula outlines. Patients were exposed to medical experiments and to the camera in the name of science. Later some sciences were proved to be pseudoscience, and also the ethics of medical photographic practices became questionable. Photographs that once were scientific proof of mental illness would later be seen as exploitation of patients. However, photographic representations of sick people have not been limited only to the walls of the hospitals or to the hands of scientists: artists and photojournalists have also contributed to the canon of images.

This chapter is an overview on how sickness has been represented in photography, and especially in art photography. Photographs originally produced for purposes other than art, even if later shown in a museum or a gallery, are not the main interest of this research as the medical photographs from the nineteenth century have been studied extensively, for example by Baer 1994, Didi-Huberman 2004, and Biernoff 2010, 2012.¹⁸¹ This research aims to examine how artists using photography as their medium have wanted to depict sickness, illness and disease.

I will first briefly outline how photography has, throughout its history, intertwined with representations of sickness and the sick. Then I will look more closely at three examples of specific artworks as representative of the approach of different eras and in relation to Kleinman's concepts. Henry Peach Robinson made and exhibited arguably the very first art photograph representing sickness in 1858. Robinson's *Fading Away* is a staged image portraying consumption (tuberculosis). British Jo Spence

180 A Sekula, 'The traffic in photographs', *Art Journal*, Vol. 41, No. 1, (Spring, 1981), p. 15–25, 1981, p. 22
181 G Didi-Huberman, *Invention of hysteria: Charcot and the photographic iconography of Saltpêtière*, The MIT Press, 2004. And U Baer, 'Photography and hysteria: Towards a poetics of the flash', *Yale journal of criticism*, Spring94, Vol. 7 Issue 1, 1994. Also S Biernoff, 'Medical archives and digital culture', *Photographies* 5:2, 2012. And S Biernoff, 'Flesh poems: Henry Tonks and the art of surgery', *Visual Culture in Britain* 11(1), 2010.

was one of the best-known photographers to make works about illness in the 1980s. Her artworks on sickness and illness span more than a decade. Raphaël Dallaporta's book *Fragile* (2010) takes a stand outside the common trend of representing the illness experience and looks specifically at disease. I have chosen these three examples because of their historical weight but also to be able to consider the representational aspects of each in terms of sickness, illness and disease.

Before photography, in the 1700s, doctors observed and experimented on patients in a quest to find the scientific truth of various sicknesses: 'The clinical gaze is a gaze that burns things to their furthest truth.'¹⁸² In practice it was the rich who invested in the clinics and hospitals, and the poor and the sick who gave in to being spectacles in order to benefit from the experiments. In other words the poor became a source of '*objective interest* for the science and *vital interest* for the rich.'¹⁸³ The emergence of a new technology, the camera, did not change this.

In the mid-nineteenth century, the camera was perceived as an ideal scientific tool, as seeing equalled knowing. According to Allan Sekula, photography 'fulfilled the Enlightenment dream of a universal language.'¹⁸⁴ At the same time photography was invented, objectivity emerged as a scientific value:

'[M]en of science started to fret openly about a new kind of obstacle to knowledge: themselves. Their fear was that the subjective self was prone to prettify, idealize, and [...] to see what it is hoped to see'.¹⁸⁵

For contemporaries, objective, scientific images were in stark contrast to subjective, artistic images; and the terms mechanical photography and aesthetic photography were used as opposites.¹⁸⁶

It was the critics who drew the line between whether photography was art or science, as was the case with the first official photography exhibition at The Salon in Paris in 1859. Summarised by the researchers Daston and Galison, Charles Baudelaire was outraged about the exhibition, as in his view 'copying nature' had nothing to do with art. Luis Figuer, on the other hand, claimed that photographs did have artistic intention and value, which could not be undermined by a simple medium. Things were scandalous the other way round too, with art infecting science, especially when it turned out that the Californian photographer Eadweard Muybridge had retouched his famous photographs of the galloping horse.¹⁸⁷

¹⁸² Foucault, *The birth of the clinic*, 1994, p. 120.

¹⁸³ Foucault, *The birth of the clinic*, p. 85.

¹⁸⁴ A Sekula, 'The body and the archive' in *The contest of meaning: Critical Histories of Photography*, R Bolton (ed.), Cambridge, MIT Press, p. 343–389, 1992, p. 343.

¹⁸⁵ L Daston, P Galison, *Objectivity*, Zone Books, New York, 2010, p. 34.

¹⁸⁶ Daston, Galison, *Objectivity*, 2010, p. 133.

¹⁸⁷ Daston, Galison, *Objectivity*, 2010, p. 131–132.

Photography was applied to the structures of the society; it became a tool for defining and classifying. Doctors, police, army and governmental agencies kept systematic archives of portraits. Physiognomy and phrenology used photography for their 'scientific' means. Phrenology mainly focused on the measurements of the human skull, and physiognomy refers to a practice whereby a person's character or personality can be determined from her or his facial appearance. For example, Francis Galton, Darwin's cousin, developed in the 1880s a technique in which he superimposed drawn portraits of people to reveal the most common features of the group. Galton believed that these revealed characteristics could be used as a tool to make diagnoses and to recognise criminals even before they had actually committed a crime.¹⁸⁸

'No longer would pattern recognition be left to the artists. Murderers or violent robbers could, for example, be brought into focus so that the archetypical killer could appear before our eyes. The problem of judgment, for someone like Galton, arouse with the artist, and the solution lay in automated amalgamation.'¹⁸⁹

In other words the morality Galton was concerned about was between the objective (science) and the subjective (art), and not with the ethicality of physiognomy.

Phrenology and physiognomy were abandoned in the late 1800s as pseudoscience, but photography remained an important tool for doctors and other medical practitioners. By 1859 cameras were being used for documenting disease in Germany, France, England and the United States. The first paper on medical photography was published in 1855, and a journal dedicated to the same subject in 1894.

'It was not a development to be stopped by complaints that the unbridled use of photography in medical practise had gone beyond discretion and ethics', academic John Tagg writes about medical photography.¹⁹⁰

Photographing diseased body parts is still a common practice in medical literature, however patients' faces are no longer usually shown.¹⁹¹ Henry E. Sigerist notes that one should remember that medicine is not a natural science: 'Methods of science are used all the time in combating disease, but medicine itself belongs much more to the realm of social sciences because the goal is social.'¹⁹²

¹⁸⁸ Wells 2009, p. 164–167 and Bates 2009, p. 71.

¹⁸⁹ Daston, Galison, *Objectivity*, 2010, p. 169.

¹⁹⁰ J Tagg, *The burden of representation. Essays on photographs and histories*, Macmillan Education Ltd Houndmills, Basingstoke, Hampshire, London, 1988, p. 81.

¹⁹¹ D Lupton, *Medicine as culture*, 2003, p. 76.

¹⁹² H E Sigerist, *A history of medicine, Volume 1, Primitive and archaic medicine*, Oxford University Press: New York and Oxford, 1987, p. 14.

The earliest British medical photographer Dr. Hugh W. Diamond (1809–1886) believed that photographs of his mentally ill female patients could cure the patients from their self-delusions. For Diamond photographs were useful patient records and scientific proofs of his patients' current mental states, but most of all they were a cure. In 1856 Diamond presented a paper before the Royal Society in which he stated that he was able to cure a female patient of her delusion of being a queen with the help of photography. Diamond had shown the patient portraits of other patients who also imagined being royalty, and the conversation following these photography sessions led to the patient's cure in four months.¹⁹³

Diamond documented his patients at the Surrey County Lunatic Asylum outside of London in the 1840s. Despite Diamond's declaration in his paper that photography worked as a cure, he never photographed his patients again after he left the Surrey Asylum and opened his own clinic in 1858 until his death in 1886.¹⁹⁴

Although Diamond actively highlighted the medical significance of his photographs as a cure, researcher Laurie Dahlberg, who has examined a previously unknown album of Diamond's photographs, argues that Diamond was also experimenting with the artistic side of photography.¹⁹⁵ Diamond was one of the founding fathers of the Royal Photographic Society, and his photographs of the patients were shown at Britain's first photography exhibition at the Royal Society of Arts in 1852.¹⁹⁶

Dahlberg notes that Diamond was taking photographs of many things other than just his patients: ordinary people, still lifes, and documentary photographs of antiques.¹⁹⁷ Despite the fact that photography was, at the time, still new and a lot of people experimented with it in various ways, Laurie Dahlberg sees that the prominent view of Diamond as a psychiatric photographer is too narrow. She argues that especially women were Diamond's muses in science but also in art. Another thing she highlights is that Diamond inspired and mentored Henry Peach Robinson, who can be considered as one the first fine art photographers of the time.¹⁹⁸ Robinson's photograph *Fading Away* (1858) depicts a young girl dying of tuberculosis. The photograph is staged and comprised of five different negatives. I will introduce Robinson's photograph in more detail later in this chapter.

193 H W Diamond, 'On the application of photography to the physiognomic and mental phenomena of insanity', read before the Royal Society in 1856 in S L Gilman (ed.), *The face of madness. Hugh W. Diamond and the origin of psychiatric photography*, Echo Point Books & Media, Brattleboro, Vermont, 1976, p. 23–24.

194 S L Gilman (ed.), *The face of madness*, 1976, p. 10–11.

195 L Dahlberg, 'Dr Diamond's day off', *History of photography*, 39:1, 3–17, 2015, p. 1.

196 R Landsdown, 'Photographing Madness', *History today*, September 2011:47–53, p. 47.

197 L Dahlberg, *History of photography*, 2015, p. 7. Also S L Gilman (ed.), *The face of madness*, 1976, p. 7.

198 Dahlberg, *History of photography*, 2015, p. 7.

The Parisian asylum of Salpêtrière became the locus of medical photography of the insane. *Photographic Iconography of the Salpêtrière* was published in three volumes between 1877–1880. J. M. Charcot, head of the asylum, and Albert Londe, head of the asylum's photography, launched the periodical *New Iconography of the Salpêtrière* in 1888, and it ran until 1918.

'Charcot and Londe presented an image of the insane as the hysteric, an image that dominated the visualisation of the insane well into twentieth century [...] Their classificatory system was as fictive as were the actions of their "pet" patients who quickly learned to act out the stages of hysteria expected by the head of the hospital and were then photographed.'¹⁹⁹

Not everyone believed that photographs could be of help in treating the insane. One of the disbelievers was Charcot's student Sigmund Freud, who wanted to concentrate on listening to the patient.²⁰⁰

In art, at the end of 1880s, naturalism emerged as a reaction to the artistic composite images mostly made by Henry Peach Robinson and Oscar Rejlander and to the mass-produced genre images.²⁰¹ Nature was supposed to be photographed as it is, and no manipulation of the negatives was allowed.²⁰² Naturalists were interested in the beauty of landscapes and nudes. The art photography of the era concentrated on what is beautiful and entertaining while 'mechanistic photography' served science by for example showing how animals moved beyond the scope of human eye.²⁰³ Sickness seems not to have fit into the expectations of art photography to be beautiful and entertaining.

For the hundred years following Robinson's *Fading Away*, there seems to be very few, if any, art photographs of sickness. However, I have not traced anthologies of individual photographers, but looked at general history books on photography (Rosenblum, 2007, Frizot, 1998), and in these sickness has not been a relevant theme in an art context though prevalent in photojournalism. The only exception I found was modernist photographer Paul Strand's photograph of a blind woman with the sign 'blind' hanging from her neck taken in 1916.²⁰⁴

199 Gilman, *Disease and representation*, 1988, p. 43.

200 Gilman, *Disease and representation*, 1988, p.43–44.

201 N Rosenblum, *A world history of photography*, fourth edition, Abbeville Press Publishers, New York, London, 2007, p. 237.

202 Rosenblum, *A world history of photography*, 2007, p. 238.

203 Rosenblum, 2007, p. 297.

204 The Metropolitan Museum of Art, Heilbrunn Timeline of Art History, accessed May 10, 2017, www.metmuseum.org/toah/works-of-art/33.43.334/

During these hundred years, photography and the role of the photographer changed significantly: advertising, montage, collage, journalism, straight photography, new objectivity, photography books, snapshots, and museum exhibitions arose. There was a significant increase in the number of photographers, and available techniques and also the uses of photography, which also meant ‘that artists were able to expand their horizons, confront new kinds of subject matter, and embrace new concepts and ideologies.’²⁰⁵

In 1979, Roland Barthes wrote that everything in society has transformed into images.²⁰⁶ Everything was photographed, also sick and suffering, just rarely for art, but for photojournalism and private use. However, some genre photography diminished. For example photographing the dying and the dead in private homes had been a common mourning practice in the mid-nineteenth century, but a hundred years later the practice had slowly disappeared and documenting illness and death became inappropriate even in homes.²⁰⁷

The emergence of photojournalism and social photography produced a wide range of images of malnourished, poor and disabled people, from Jacob Riis’ slum photographs in the late 1880s, Dorothea Lange’s *Migrant Mother* and Robert Capa’s *Death of a Loyalist Soldier* in 1936, W. Eugene Smith’s *Life* magazine reportages in 1940s and 1950s, to Sebastião Salgado’s photographs of the poor and malnourished in the 1970s and 1980s, and to numerous other documentary photographs. One particular example is W. Eugene Smith’s and Aileen Smith’s book *Minamata*, published in 1975, which depicts the outcome of mercury being released into the ocean, causing Minamata disease. In the most known photograph of the series, a mother holds her daughter, Kamimura Tomoko, who is blind, deaf and whose legs are undeveloped.

However, these socially motivated photography projects faced new challenges in the 1980s according to historian Naomi Rosenblum:

‘One was the observation on the part of some critics that photographing the poor (other than someone within the community) was a form of exploitation.’²⁰⁸

Susan Sontag questioned in the 1970s the ethics of photographing suffering people without arousing compassion. According to her, these

kinds of photographs might lower our threshold of what people find tolerable, but they also numb and make people less prone to help others in real life.²⁰⁹

Sontag wrote especially about Diane Arbus’ photographs. Arbus photographed dwarves, giants and mentally challenged people in the US mainly in the 1960s and 1970s. Sontag writes: ‘Her works show people who are pathetic, pitiable, as well as repulsive’²¹⁰ and that these photographs ‘make a compassionate response feel irrelevant.’²¹¹ Also as curator Carol Squiers points out that in the 1980s photographers depicting AIDS were criticised especially if they showed the diseased people as pitiful victims. In 1988, ACT UP group demonstrated in front of the Museum of Modern Art against Nicholas Nixon’s exhibition *People with AIDS*. The headline of the fliers read: ‘No More Pictures Without Context’.²¹²

Especially in the 1980s photographers turned the camera towards themselves to document their own or their family member’s sicknesses. According to historian Stanley Burns, the reason why documentary photographers started to make projects about the sick, dying and dead in the 1980s was because death and dying had become so depersonalised in modern society, that there was a vacuum for individual expressions of illness²¹³.

In the late 1980s, the human body was the subject in numerous photography works, which commented on gender, ageing, race, and modifications of the body. According to academic Liz Wells, it was the AIDS epidemic and the rise of critical photographic theories that gave rise to the unforeseen interest in the human body in the late 1980s.²¹⁴

Stanley Burns also notes that in the 1990s, at least in America, people with a long-term sickness could stay at home until the death, and this in turn resulted in a new emergence of a genre of images documenting death and dying at home. Also, for example breast cancer, which had been a secret family matter until the 1980s, became a public topic in America. Private individuals and public health advocates started talking about breast cancer, and the press started covering survivor stories and interviewing relatives of those who had died.²¹⁵

205 Rosenblum, 2007, p. 297.

206 R Barthes, *Camera lucida: Reflections on photography*, Hill & Wang, New York, 1981, p. 118.

207 R Pardo, M Morcate, ‘Illness, death and grief: daily experience of viewing and sharing digital images’, in *Digital photography and everyday life*, E Gómez Cruz and A Lehmuskallio (eds.), Routledge, London and New York, p. 70–85, 2016, p. 70.

208 Rosenblum, 2007, p. 544.

209 S Sontag, *On photography*, 2011, p. 40.

210 Sontag, *On photography*, 2011, p. 33.

211 Sontag, *On photography*, 2011, p. 40.

212 C Squiers, *The body at risk*, 2005, p. 156.

213 S B Burns, *Sleeping beauty. Memorial photography in America*, Twelvvetrees Press, 1990, appendix Death in America: A Chronology.

214 L Wells (ed.), *Photography: A critical introduction*, London, Routledge, 2009, p. 161.

215 S Braun, ‘The history of breast cancer advocacy’, *Breast Journal*, May 2003 Supplement 2, Vol. 9, 2003, p. 102–103.

Also artists started covering breast cancer, for example Hannah Wilke (1940–1993) examined her own and her mother’s breast cancer experience. Wilke’s large photographic prints depicting her own and her mother’s illness and treatment were exhibited and awarded after her death in numerous museums and galleries. Not all art photography about sickness was exclusively personal, some was also political. Jo Spence (1934–1992) made political art about her own breast cancer in the 1980s. She was keen to question the representations of the sick body and to problematise Western medicine. Robert Mapplethorpe enraged museum curators during the AIDS epidemic with a self-portrait which showed a horsewhip inserted into his anus.

During the same century, the camera and other visual technologies became more than ever extensions of human vision, showing parts of the body that had never been visible before. As new medical research methods were developed (ultrasound, CAT, MRI), the human body morphed into scientific data.²¹⁶ The new visual methods, like ultrasound, overrode the old use of traditional photographs as a source of medical knowledge. Objective, mechanical photography had actually lost most of its scientific value already in the beginning of the 1900s as it was acknowledged that straight, un-manipulated and un-interpreted photographs were too particular, too accumulated, too specific, to be able to communicate scientific information.²¹⁷

‘By the mid-twentieth century, objectivity and subjectivity no longer appeared like opposite poles; rather, like strands of DNA, they executed the complementary pairing that underlay understanding of the working objects and science.’²¹⁸

In the twenty-first century, photography stories about personal illnesses have become more common online than before. Professor Rebeca Pardo and Montse Morcate, who have researched photographic representations of illness, death and grief in social networking sites, suggest that these types of images are becoming acceptable again.²¹⁹ Their data show that there is an increase in the representations of illness and death in social networking sites, whereby people are sharing their personal encounters with illnesses. Pardo and Morcate describe the produced images as sort of commonplace family photos, different from the representations for example in the arts.²²⁰

216 L Wells, *Photography: A critical introduction*, 2009, p. 162–186. Also D Bate, *Photography: the key concepts*, Berg, New York, 2009, p. 48–71.

217 Daston, Galison, *Objectivity*, p. 36.

218 Daston, Galison, *Objectivity*, p. 36.

219 Pardo, Morcate, *Digital photography and everyday life*, 2016, p. 70.

220 Pardo, Morcate, *Digital photography and everyday life*, 2016, p. 81.

Nonetheless, diary-like photographs of illnesses are also common in art photography. Photographer Phillip Toledano pointed his camera towards his father’s struggle with a memory disease in *Days with My Father* (2010). Henrik Malmström’s *On Borrowed Time* (2010) shows the last few months of the artist’s sister dying of cancer. Nancy Borowick documents in *Cancer Family* (2015) her parents being sick with cancer and dying from it.

Art photography works that deal with disease, rather than the illness experience, are more rare. Max Aguilera-Hellweg has photographed invasive surgeries with a large format camera. His book *The Sacred Heart, An Atlas of the Body Seen Through Invasive Surgery*, was published in 1997. Raphaël Dallaporta’s *Fragile* (2010) portrays sickness post-mortem. Dallaporta photographed, in a visually stylised way, the failed organs responsible for a person’s death.

Next I will introduce in more detail three artworks relevant to the history and the topic: Henry Peach Robinson’s *Fading Away*, Jo Spence’s *The Picture of Health?* and Raphaël Dallaporta’s *Fragile*, and link them to Kleinman’s definitions of sickness, illness and disease.

3.3.1. Sickness and Henry Peach Robinson’s *Fading Away*

Henry Peach Robinson (1830–1901) was one of the first photographers to actively push photography to be considered as fine art in Great Britain in the mid to late 1800s. Robinson was frequently awarded in exhibitions and wrote at least nine books and over a hundred articles on photography during his more than forty year career. Throughout Robinson’s career, he underscored the importance of imagination, ideas and inventions instead of the mechanistic execution of making photographs.²²¹ Robinson made images by combining multiple negatives. Despite the fact that his contemporaries criticised these composite images, for Robinson this technique was just a means to a higher goal: artistic expression. For him imagination was art, and photography was the way to give ‘pictorial embodiment’ to the ideas.²²²

Robinson was a commercial studio photographer, who dreamed of being a painter.²²³ His most well-known composite photograph *Fading Away* was exhibited at the Crystal Palace in London in 1858. The photograph is made



Henry Peach Robinson: *Fading Away*, 1858.

221 L D Coleman, *Pleasant fictions: Henry Peach Robinson's composition photography*, The University of Texas, Austin, 2005, p. 60.

222 H P Robinson, *Pictorial effect in photography: Being hints on composition and chiaroscuro for photographers*, Piper & Carter, London, 1869. Also Coleman, *Pleasant fictions*, 2005, p. 130.

223 Coleman, *Pleasant fictions*, 2005, p. 13.

from the combination of five different negatives and it depicts a young woman dying on a bed surrounded by two older women and a man looking out the window. The young woman is a model who is pretending to be dying of consumption, later known as tuberculosis. David Bate writes:

‘The photograph shows an angelic death watched over by the girl’s mother and sister. The father turns away towards the outside world, his arm signifying that he hides his grief from them, and us. The women are facing towards this death, a domestic event inside a room that is thus defined as a feminine space. The models are posed to create a harmonious composition, implying a good and beautiful death’.²²⁴

At the exhibition, *Fading Away* was shown together with a part of Percy Shelley’s poem *Queen Mab*. The poem is in total 17 verses and its main themes are death and utopia. Robinson used six verses of the poem, which describe the beauty of death.²²⁵ David Coleman, who wrote his dissertation on Robinson’s work in 2005, sees that combining the photograph with a fictive poem was to emphasise that *Fading Away* was also fictive.²²⁶

Fading Away was exhibited six times within two years and it was displayed for months in the print seller’s windows.²²⁷ It was also ‘one of the most discussed single images in the British photography journals of nineteenth century’.²²⁸ Ten years after *Fading Away*, Robinson published the book *Pictorial Effect in Photography* (1869), which instructs photographers how to make artistic photographs. Robinson was also one of founders of the New English Art Club in 1892. The aim of the club was to push photography to the highest forms of art.²²⁹

Robinson’s aim was to embody his artwork with sentiment, and according to researcher David Coleman, Robinson also succeeded in this with his controversial and unusual subject matter. Coleman highlights that although sickness as a theme was not common for photographs it was for Victorian paintings and also for Romantic literature; when artists died of tuberculosis ‘it became a poetic trope for genius’.²³⁰ At the time of Robinson’s photograph, the cause of tuberculosis was unknown and there was no effective treatment. However Coleman notes that when poets and painters

approached the topic of disease, they most often used it as a tragic symbol rather than showing the actual manifestations of a disease.²³¹

According to Coleman, Robinson went to great lengths to make sure that the photograph would be received as an art photograph. First, he constructed the image from five negatives; secondly, he exhibited it alongside a poem in a similar vein as numerous painters at the Royal College had done; and thirdly, he chose a theme that was culturally important and prominent in painting and literature. For Robinson, it was important to make a fictive photograph, staged with models, because he believed if the scene was real, it would be much too awful to bear.²³²

It is interesting that Robinson considered an image to be too much if real because, at the same time as he produced his own photograph, highly stylised post-mortem photographs were being produced in great number for private use. In these studio portrait images, most commonly a dead child was placed clothed in his or her parents’ arms or lap, sometimes appearing to be sleeping, sometimes with the eyes open. These were often the only images of the deceased. According to historian Stanley Burns, great artistic effort went into making these images. For example one daguerreotype from 1848 depicts a dead girl in her father’s arms. The mother sits next to the father and rests her elbow on the father’s shoulder. At the left of the photograph, behind the mother, there are medicine bottles on a table. In the book *Sleeping Beauty, Memorial Photography in America*, the daguerreotype is titled *Mother and Father with Dead Daughter, Useless Medicine Bottles on Table*.

In the 1850s, in the Western world, death was not feared as before. Burns describes that death was, for those who had had proper lives, ‘a sort of graduation ceremony to advanced celestial instruction’.²³³ Also at the time of *Fading Away*, general anaesthesia had been introduced. According to Burns this marked a turn at which the concepts of death and sleep were bound together. Morphine as a pain reliever had also just entered the markets – a drug named after Morpheus, the god of dreams. Before efficient pain relievers, death was in almost every case, regardless if caused by a disease or an accident, a great agony.²³⁴ Despite the great number of post-mortem photographs, they were only for private use; they were hung on the walls at home and carried in wallets. Robinson’s image was public, but also the person was not yet dead, and it looked so realistic that some people misidentified the image to depict real events.

Despite Robinson’s attempts to highlight the fictitious character of the photograph, it was still too painful to see for many people. Also the use

224 D Bate, *Art photography*, Tate Publishing, London, 2015, p. 33.

225 The same poem was later reworked, and goes by the name *The Daemon of the world*. The verses Robinson used from the poem: Must then that peerless form, / Which love and admiration cannot view / Without a beating heart, those azure veins / Which steal like streams along a field of snow, / That lovely outline, which is fair / As breathing marble, perish! Coleman, *Pleasant fictions*, 2005, p. 118–119.

226 Coleman, *Pleasant fictions*, 2005, p. 129.

227 Coleman, *Pleasant fictions*, 2005, p. 119–120.

228 Coleman, 2005, p. 119.

229 N Rosenblum, *A world history of photography*, 2007, p. 309.

230 Coleman, *Pleasant fictions*, 2005, p. 122.

231 Coleman, 2005, p. 123.

232 Coleman, 2005, p. 126.

233 S B Burns, *Sleeping beauty*, appendix Death in America: A Chronology, 1990.

234 S B Burns, *Sleeping beauty*, 1990.

of the poem alongside the photograph was overlooked in the press.²³⁵ For the correspondent of *The Photographic News*, the theme of the photograph was unbearable and unsuitable for an exhibition, and others commented that Robinson’s work was not a work that could be hung up on a wall.²³⁶ In addition, despite Robinson’s effort to make sure that viewer understands that they are looking at a constructed photograph, many still believed that the photograph depicted real people instead of models.²³⁷ Coleman argues that:

‘Fading Away’s artistic mediation could not entirely overcome, nor even compensate for, its real photographic space. There was too much realism—the subject was too topical and the characters were too contemporary.’²³⁸

In the diagram presented later in this chapter, which aims to give an overview on art photography works in relation to Kleinman’s differentiation between sickness, illness and disease, I have placed *Fading Away* between sickness and illness, as it is more about consumption in general, depicted through a healthy anonymous model, than it is about someone’s specific illness experience. The photograph is about how photography can represent a condition and bring about an emotional response in the audience.

Still, although Robinson succeeded in making a highly effective photograph, photography historian Naomi Rosenblum notes: ‘Robinson avoided such emotion-laden subjects again [...]’²³⁹ He did not touch the topic of sickness again but continued to make composite images and to write about photography as an art form.

3.2.2. Illness and Jo Spence’s The Picture of Health?

One of the most well-known photographers to make works about illness is British photographer Jo Spence (1934–1992). She made various works around her own breast cancer and leukaemia spanning more than a decade. She was among the first artists to use photography and roleplay to criticise identity politics. Spence holds an iconic position in British feminist art practice.²⁴⁰ Despite Spence being most well-known for the

works related to illness, she did have an artistic career already before she was diagnosed with breast cancer in 1982. She was a political artist who especially wanted to problematise the representation of the female nude. British writer and scholar David Bate interprets that Spence used her body as ‘home’, as what constitutes her:

‘Throwing off the cloak of decency, or in this case her medical gown, Spence exposes the sense of disunity and fragmentation she experienced [...] The geometric space of the human body itself comes under assault, not only from the medical gaze to which this picture was addressed, but also to the physical image of her body.’²⁴¹

Spence used photography as a ‘cathartic tool’, as well as a document, political manifesto and a therapeutic tool.²⁴² When Spence started making art about her illness she noticed that the art world was incapable of reacting: ‘I put up these photographs of my illness and progress and I got no feedback from anyone.’²⁴³ Spence says in an interview that she wanted to show other ways to talk about illness, but the art world did not seem to have a vocabulary to talk about illness in general or especially cancer back then.

‘Looking back, I’d say that the more silence there was, the more I upped the ante, the more I was determined to be heard. The problem was that I split myself across the art world, the photography world, the health world. So I had to do the job three times over’, Spence says in an interview in *Artpaper USA* in 1991.²⁴⁴

Critic Maria Walsh writes that it is this multitude of Spence’s approaches, and especially the therapeutic aspects of her works, that resulted in galleries having a complex relationship with her work.²⁴⁵ In other words, the curators and critics are faced with the problem that Spence’s work leaks over and around the boundaries between what is traditionally considered high art and what is considered art therapy.

‘Spence’s work on taking control of her cancer treatment by using photography and graphic media might also seem anachronistic today when information, albeit select and with profit motives, is so accessible. Yet it is still empowering to witness her subjectivisation of the alien experience of illness, especially in relation to our current medical climate that cajoles us to take control of our bodies so that governing bodies can abdicate responsibility.’²⁴⁶

235 Coleman, *Pleasant fictions*, 2005, p. 128.

236 Coleman, 2005, p. 121–122.

237 Coleman, 2005, p. 135.

238 Coleman, 2005, p. 154.

239 N Rosenblum, *A world history of photography*, 2007, p. 229.

240 M Walsh, ‘Jo Spence work (Part I & II)’ *Art monthly*, Jul/Aug2012, Issue 358, p. 29–30.

241 D Bate, *Art photography*, Tate Publishing, London, 2015, p. 142.

242 A Lovatt, ‘Jo Spence’, *Artforum international*, Oct2012, Vol. 51, Issue 2, p. 276.

243 J Spence, J Stanley, D Hevey, (eds.), *Cultural sniping: the art of transgression by Jo Spence*, Routledge, London, 1995, p. 213.

244 J Spence et al., *Cultural sniping*, 1995, p. 216.

245 M Walsh, *Art monthly*, 2012, p. 29–30.

246 Walsh, 2012, p. 30.



Jo Spence: *Cancer Shock*,
Photonovel, 1982



Jo Spence and Terry Dennett: *The
Picture of Health?*, 1982–86.

Jo Spence's works have been shown over recent years at Space and Studio Voltaire in London in 2012 and at White Columns in New York in 2013.

Following Jo Spence's diagnosis, she worked on different bodies of work all addressing her illnesses, and in the end mortality. Often all the works are grouped under the umbrella of an exhibition titled *The Picture of Health?* At the Jo Spence Memorial Archive site, curated and owned by one of Spence's collaborators, her illness-related works are divided into smaller themes: *Cancer Shock*, *The Picture of Health? Phototherapy*, *Narratives of Dis-ease*. With all her works, Spence wanted to find a visual language to communicate about illness and being ill. She noted that medical language was sufficient as a tool for doctors to diagnose and treat disease, but it reduced people to bodies. Spence was not only interested in the identity politics, but she wanted to share all her knowledge on the topic. She wrote for photography and art journals, but also to wellness journals and spoke at health conferences.

Cancer Shock, made in 1982, is a series of photonovels, photographs, newspaper articles and personal texts incorporated into posters. The series starts with the shock of the medical invasion of the body, but moves into questioning the victim position and modern medical practices. The images vary between Weegee-style black and white images taken with a straight flash and diary-like colour photographs. The photographs are combined and shown as posters mimicking yellow press aesthetics; for example one full body image is a cut-out and her mastectomy scar is shown in multiple photos varying in size from medium scale to detail.

In *The Picture of Health?*, made in collaboration with Terry Dennet in 1982–1986, Spence used photography to make a historical narrative of her breast cancer operation experience. The series includes her well-known photographs of her in a mammography machine and a photograph of her showing the mastectomy scar while wearing a helmet. Spence plays in her work with cultural stereotypes of how ill people should look and how they shouldn't. Spence examines how to reconstruct the representations of a sick person, how to make oneself a subject rather than of being an object of Western medicine. The series mixes grainy black and white and colour images, and also incorporates texts written directly on her own body. In contrast to *Cancer Shock* more weight is given to individual compositions in the series. The angles of the photographs alternate between depicting Spence from a neutral perspective to looking up at the nurses from a notably low perspective.

Phototherapy is a series of self-portraits Spence made in collaboration with Rosy Martin in 1986–1989. Their starting point was that portraits are not stable 'truths' about the person who was in front of the camera, but are

instead a malleable tool with which to play, transform, question and discard a multitude of selves. The images resemble Cindy Sherman's conceptual portraits as Spence adopts a different role in each photograph. Thus, instead of carefully controlled lighting, Spence's images are rough and raw; the lighting alternates from soft overall light to harsh light coming from the side.

Narratives of Dis-ease, made in collaboration with Dr. Tim Sheard, is a commentary on body politics and especially on the representation of the female body in relation to a mastectomy. In this series, Spence questions the standards for beauty and body. In one image she has written 'monster' across her naked chest. The photographs have the same playfulness as images in *Phototherapy*, but this time Spence is naked in most of the images and they are also more tightly framed than in the previous series. The images depict staged emotional states of being sick and are unpolished, contributing to the overall roughness of the images.

Final Project, made in 1991–1992, examines death and mortality in an explicit way. The series is a combination of frank, sometimes even comical images of masks and skeletons, and aestheticised dream-like, composite images. The photographs are taken farther away than in all of the previous series and are also more 'beautiful' compared to the earlier works. Jo Spence died from leukaemia in 1992.

As a whole, Spence's works are rough, often inadequately lit and sometimes also purposefully badly composed. Many of Spence's series mix black and white with colour images. Her photographs seem to be decisively un-aestheticised, which enhances the gruesomeness of the images. The images go straight to the topic, without beautifying or making it in any way easier for the viewers. The exception is *Final Project*, which entails beautiful landscapes and composite images in addition to the signature boldness and humour in the previous works.

In general Spence had a blunt take on the topic and used photography for whatever means she saw fit, including phototherapy, photonovels, and art, making it hard for the critics and curators to decide: are her photographs first and foremost art that communicates something bigger about illness and body politics or are they mainly just her own very personal phototherapy? For Spence, her illnesses were most of all a crisis of representation but also: 'This isn't just an art work. This is an actual body that someone inhabits.'²⁴⁷ Curator Jorge Ribalta poits out that:

'Spence's work was a strong demonstration that the self-experimentation, self-education, and self-learning involved in true artistic play cannot be frozen into art commodities but must constantly



Jo Spence and Rosy Martin:
*Phototherapy (Infantilization –
Mind/Body)*, 1984.

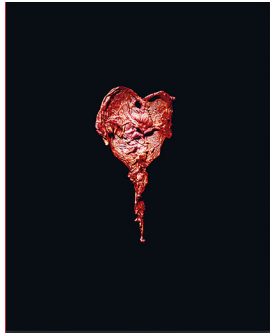


Jo Spence and Dr Tim Sheard:
Narratives of Dis-ease (Exiled),
1990.



Jo Spence and Terry Dennett,
*Final Project (death rituals and
return to nature series)*, 1991–92.

247 J Spence et al., *Cultural sniping*, 1995, p. 214.



Raphaël Dallaporta: *Dura mater*, in *Fragile*, 2011.

resist the reified condition of the art object in the bourgeois public sphere.’²⁴⁸

Jo Spence’s artworks are not just about illness despite the fact that she is making art of her own personal experiences. The reason why I have placed Spence’s work between illness and sickness in the diagram shown later in this chapter is the politicality of her works. Spence is very clearly vocalising in her images the criticism towards Western medicine and especially the subject/object position in which patients are often placed. She is questioning the ownership of her own body parts and the roles available to sick people in general. Spence’s work is not only about her personal experience but also about being a patient in general in society. At the same time she is negotiating the position of photography as art and as therapy.

3.3.3. Disease and Raphaël Dallaporta’s *Fragile*

The French photographer Raphaël Dallaporta (1980) made a book titled *Fragile* in 2011. *Fragile* consists of 23 photographs of human organs – each responsible for a person’s death – after being removed from the body. Although the images are shot during autopsies, Dallaporta’s work can be seen to focus on the event of sickness (or accident or violence) before death. He is looking at the point in time where the body failed or gave in, that is, why it died. All the photographs are taken against a black background, and the depth of field reveals a lot of detail. The organs are placed in the middle of the portrait frame surrounded by the deep black background; they seem to be hanging in the middle of dark emptiness. The photographs are rich in colour and the moistness of internal organs is visible on the surfaces, making the photograph appear deliciously colourful but corporeally gruesome.

The photographs are accompanied by texts from the police reports. In addition to the organs, the book ends with four close-up photographs of the bodily humors: blood, yellow bile, black bile and phlegm. The work has been exhibited as a part of his Observation exhibition amongst others in The Netherlands, Luxembourg, Germany and France. In 2008, the series, not yet completed, was shown at the New York Photo Festival under the title Autopsy. I interviewed Dallaporta in Arles, France in July 2015.

248 J Ribalta, ‘Molecular documents: Photography in the post-photographic era, or how not to be trapped into false dilemmas’, *The meaning of photography*, R Kelsey, B Stimson (eds.), Yale University Press, New Haven/London, 178–185, 2008, p. 182.

Dallaporta’s series and his interview emphasise disease as a temporal and spatial place between life and death but also touches on the complexity of showing images of people’s insides. The first time Dallaporta saw a dead body was during an autopsy. He did not take any photographs, but one was taken of him. In the photograph, Dallaporta is whiter than the person being autopsied. He says in the interview:

‘The first day there was a grandpa, dry, dead, obviously dead. But what happens to your brain when you have never seen a dead person, is that you keep on thinking, it’s obvious that he’s dead, but they still do all the procedures to make sure [...] so your brain is instantly trying to solve this issue, is he dead or alive?’²⁴⁹

The pale photographer left the room and sat at the doctor’s office:

‘When I was in his office, I solved the issue, if he’s dead or alive, and I regained colour immediately [...] I re-entered the room, and they started to open the body, and that was incredible, the amount of colour there. And I said, “This is where I want to do my project.”’²⁵⁰

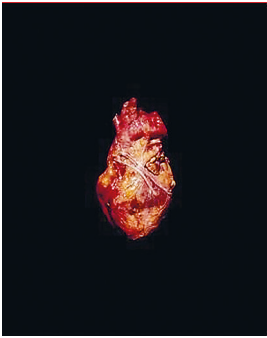
Dallaporta continued to photograph autopsies for four years because he really did not know how to stop. Another photographer, Max Aguilera-Hellweg, who has photographed invasive surgeries, writes in his book that the reason he took the photos was to make people less afraid of death. Dallaporta’s reason, by contrast, is to generate melancholy:

‘It is really not about the magic of the life but the beauty, the strong intensity of life, because we have this thing [death] coming, and we don’t know how and when, and there is no way to get ready because especially in our culture it still is the biggest taboo. I am not doing my project to feed curiosity. People can be interested and wanting to look at it closely, but it [the project] is not to cure, it’s to develop melancholy.’²⁵¹

Melancholy for Dallaporta is not a sickness or depression but a stage to reach, a beautiful place to be:

‘The depression comes when you refuse to be melancholic and you don’t want to think about death, you’re escaping. But if you really confront yourself with this need to live, if you really get deep into this question and so on, you find knowledge about fragility, for example.’²⁵²

249 R Dallaporta in an interview, Arles, France, July 10th 2015. (Transcription, p. 12.)
250 R Dallaporta in an interview, 2015. (Transcription, p. 13.)
251 R Dallaporta in an interview, 2015. (Transcription, p. 13.)
252 R Dallaporta in an interview, 2015. (Transcription, p. 10.)



Raphaël Dallaporta: *Heart with previous bypasses*, in *Fragile*, 2011.

In other words, Dallaporta wishes to make people understand something more about themselves and their relation to death. In addition, he wishes to induce a melancholic state that makes this understanding possible. This melancholic state has also been called the artist’s disease as Susan Sontag describes in her book *Illness as Metaphor*.²⁵³

Dallaporta brings up the same theme about organs – they are ‘never supposed to see light’ – as Max Aguilera-Hellweg, who has photographed invasive surgeries. Aguilera’s photographs are discussed more in Chapter Five. Dallaporta talks the same way about a heart that never sees light except those few fragile minutes during the autopsy before it is put back into the darkness.

Dallaporta says that he is somewhat reluctant to show the project although he worked on it for four years. In *Fragile*, the organs are shown smaller than in real life and never hung vertically on the walls but rather lay horizontally on a table. Dallaporta says that he never wants to show the photographs on a computer or mobile phone screen. For him, the series is literally fragile: ‘I reduce, reduce, reduce the impact that this project should get because I will not carry a project for the wrong message.’ He tells that he does not want to be a provocateur or to upset viewers.

For Dallaporta, using photography is the most appropriate medium to document death:

‘Because of this relation with time, it’s always something that doesn’t survive. There’s a beautiful text of Giorgio Agamben, who even says as an introduction to some street photography and things, that every photograph could be the apocalypse moment, which is the death of everyone. So even photography with nothing could be this moment and it’s incredible how close it is to death no matter the subject you’re dealing with [...]’²⁵⁴

However, Dallaporta sees limits in the ability of photography to reach the symbolic level. As an example, he says that if one is shown a painting of the heart of someone who has shot himself, many will think of the passion of life, but if one sees a photograph of the same thing, the viewer has to take some unconscious level to reach the symbolic if it is reached at all.²⁵⁵

In the diagram later in this chapter, *Fragile* is placed closest to disease, a bit towards sickness. Dallaporta’s works concentrates on the understanding of life and death themselves through disease. The photographs and texts are

253 S Sontag, *Illness as metaphor and AIDS and its metaphors*, Doubleday, New York, 1991, p. 32.
254 R Dallaporta in an interview, (Transcription, p. 29.)
255 R Dallaporta in an interview, (Transcription, p. 5.)

after the illness experience and without the person or relatives; they show how death is handled officially: police reports, autopsy. The series does not read as a criticism against or a commentary about these procedures on a societal level, but looks at the fragility of the human bobbies, the organs that fail the bodies. Dallaporta draws attention to the physical fragility of the human body, and hopes to take the thought to a symbolic level, to make the viewer ponder the fragility of being a mortal. There is one important contradictory position in Dallaporta’s series and how he talks about it. He vocalises that he does not want to feed curiosity or upset, but at the same time he shows photographs of things ‘that were never supposed to see light’, such as the spinal cord, sternum and congestive brain.

This abject position of wanting to show and not wanting to show recurs in the descriptions of photography series that show bodily organs. Chinese photographer Li Zhaohui’s series *Specimen: Human Organs Under a Ruler* (2015) shows organs photographed during surgeries. Li Zhaohui writes in his statement that he chose, on purpose, soft lighting and black and white film to ‘protect the viewers from strong visual stimulation and guide them to break through the visual appearance in their minds to find the connotation.’²⁵⁶

Li Zhaohui writes that he does not want to explain his own intentions about what he wants to say with the images:

‘However it seems that what these images would try to express is very complex. I had discussed this with my friends in different fields, including photographers, doctors, writers, archaeologists and even philosophers. All of them have different opinions with this series of pictures and even some of them have totally opposite opinions.’²⁵⁷

This contradictory position can also be described as abject. Chapter Five scrutinises this very problem of wanting to look at and not wanting look at disease or bodily organs. It is also the disposition I strived to understand when making my own photography series *Removals*. The chapter will not have one clear answer but aims to help understand what confronts Dallaporta, Aguilera-Hellweg, Li Zhaohui, myself and viewers of the series.

3.4. Applying Kleinman

To provide an overview of how sickness is depicted in art photography, and to test and analyse the artworks according to Kleinman’s definitions of sickness, illness and disease, I have constructed a simple diagram,

256 Li Zhaohui, author’s webpage, accessed April 23, 2016, <http://lizhaohui.cc/specimenhuman-organs-under-a-ruler>
257 Li Zhaohui, author’s webpage, 2016.

an equilateral triangle, and plotted 67 photography artworks within it. The diagram presents an overview on art photography work in relation to sickness, disease and illness. I have categorised the photography works based on how they have been presented online, in a book or in an exhibition. The works in the diagram are photography works that have self-identified themselves as covering the topic of sickness, either naming a disease or a condition, or the aftermath of such either in titles, captions or in the introduction of the series. Photography series depicting death and the dead are only included if the images, titles or accompanying texts have a link to the theme of sickness; for example Dallaporta's *Fragile* is included since the series depicts the failed organs responsible for the causes of death but Andres Serrano's *Morgue* (1992) images are not.

The artworks in the diagram are by artists who have had solo exhibitions, or a significant number of group exhibitions, or who have published books. Some works I have been forced to exclude because there has not been a way to get a sufficient overview of the whole work. The artworks are gathered from books on contemporary photography or the history of photography, and from exhibitions and photography festivals. In addition, I have also made inquiries to major social media photography groups such as FlakPhoto, and with various photography curators and editors. Most of the works in the graph are made within the last twenty years, and most them are Western. The list of artworks is not all-inclusive; there are undoubtedly many more thematically relevant photographic artworks that could have been added. This diagram presents only 67 artworks. However, the amount is sufficient to reveal concentrations and trends in the diagram.

I am presenting sickness, illness and disease as an equilateral triangle, where sickness is at the top of the general formation as a blanket term, and illness in the left corner and disease in the right corner. An equilateral triangle is used for example in mineralogy, and population genetics as the basis of a ternary graph, triangle plot and de Finetti diagram to represent proportions of three different variables in a system, for example genotype frequencies in populations. In a triangle plot, each point in the triangle represents a composition of all three aspects.²⁵⁸ Using an equilateral diagram enables me to place photographic works in relation to all three aspects instead of under just one aspect or category: the works can be at the points, between them or in the middle. This spatial placing reveals nuances and differences between works. For example, Jo Spence's works are placed between sickness and illness as they criticise institutional structures and especially the role offered to the sick person within medicine, but at the same time they aim to convey the experience of being

258 C Stover, 'Ternary diagram', in *MathWorld*, A Wolfram Web Resource, created by Eric W. Weisstein, accessed April 7, 2017, mathworld.wolfram.com/TernaryDiagram.html

ill. Using the equilateral triangle also highlights the fact that each artwork is inherently about all the three aspects but the proportions differ.

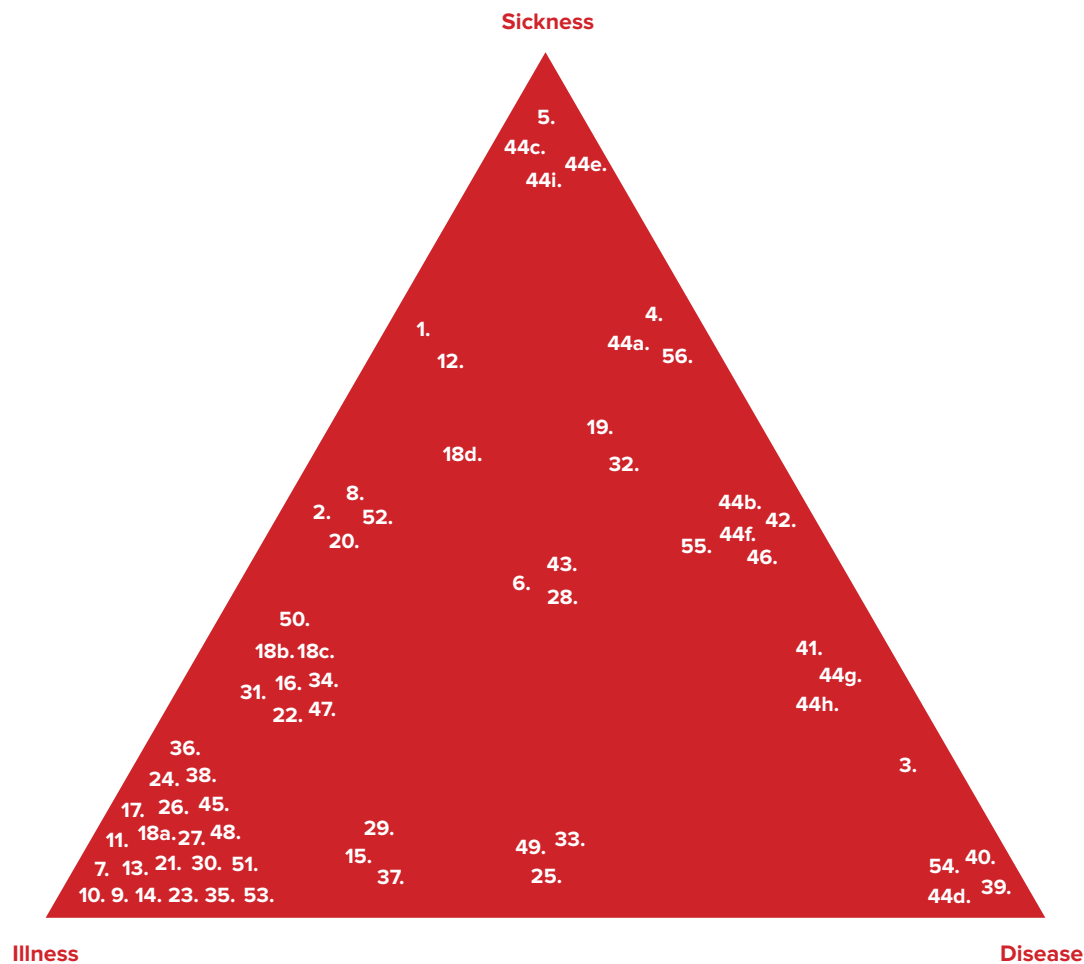
The closer an artwork is placed to the top, the more is it about sickness in general or in relation to economic, social or political power structures. The closer the work is towards the left corner, the more the works are about the individual experience of the patient or his or her close relatives. The closer the work is to the right corner, the more it is about disease seen as a medical or biomedical entity. At the dead centre of the triangle are photography works that represents all three – sickness, disease and illness – in equal proportions.

As the starting point of the diagram analysis is to place artworks, which are already cultural products, I am looking at Kleinman's definitions relatively. This is because, for example, Kleinman's disease is a biomedical interpretation of the symptoms in a medical context, and art is located outside of this context. Therefore artworks placed closest to disease are those which look at sickness objective-like, sort of as an outside observer, rather than trying to express an illness experience or comment on the institutional aspects, power structures or definitions of sickness.

The photographic works are positioned in this diagram on the basis of the photographs and the immediate text provided with them. In other words, I am looking at the whole artwork, which includes also titles and statements. I am looking at the image instead of a picture, following W.J.T. Mitchell's differentiation between a picture and an image: a picture is the physical and material thing on the gallery wall, whereas an image is the visual and mental formation of the thing in question.²⁵⁹

None of the artworks placed on the diagram are only about sickness, illness or disease; many of them have significant other qualities that touch on other themes such as art theory. However, this diagram looks at the aspect of the photographic works, which deals with representing sickness.

259 WJ T Mitchell, *What do pictures want?*, p. 140.



The Artworks

1. Henry Peach Robinson: *Fading Away*, 1858.²⁶⁰

The work is a constructed and staged composite photograph depicting a young woman dying from consumption (tuberculosis). Robinson wanted to evoke feelings in the viewer and not so much comment on a specific illness experience or specific disease. According to Robinson himself the image would have been too much if it were real. I have placed the image closest to sickness towards illness experience.



Neil Pardington: *Operating Theatre #3*, 2004. From the series *The Clinic*.

2. Jo Spence: *Various works*, 1982–1992.²⁶¹

Spence's works stem from her own illnesses, and she also used photography as therapy, but her works are political, commenting on the offered roles for the sick or the way the body is seen as an object of medicine. I have placed her works between illness and sickness.

3. Raphaël Dallaporta: *Fragile (book)*, 2011.²⁶²

The book consists of photographs of dissected organs responsible for people's deaths. The photographs are accompanied by texts from the police reports. The work looks at the biological organs evidence-like, combining the images with institutional texts. I have placed the work closest to disease, but a bit towards sickness.

4. Neil Pardington: *The Clinic*, 2003–2005.²⁶³

The work is a collection of empty institutional photographs depicting mainly operating theatres and post-mortem rooms. The series concentrates on the institutional structures of disease; placed closest to sickness towards disease.

5. David Maisel: *Asylum*, 2006.²⁶⁴

A series of photographs depicting old, abandoned asylum rooms and corridors falling apart. The *Asylum* series is a part of Maisel's book *Library of Dust* (2008). The work focuses on dilapidated institutional buildings, where the patients and the traces of disease have long disappeared; placed closest to sickness.

²⁶⁰ H P Robinson, *Fading away*, The Metropolitan Museum of Art's website, accessed Oct 25, 2016, <http://metmuseum.org/exhibitions/view?exhibitionId=%7B36d81705-241d-4934-ab02-fd7c8dbbb3e5%7D&oid=302289>

²⁶¹ Spence Jo, The Jo Spence memorial archive London, Terry Dennett, accessed Oct 25, 2016, www.jospence.org

²⁶² R Dallaporta, *Fragile*, GwinZegal, Guingamp, 2011.

²⁶³ N Pardington, author's website, accessed Oct 25, 2016, www.neilpardington.com

²⁶⁴ D Maisel, author's website, accessed Oct 25, 2016, davidmaisel.com/works/asylum/#2



Elinor Carucci: *Pain 5*, 2003.



Thilde Jenssen, *Canaries*, 2013.

6. Kathryn Parker Almanas: various works, 2005–2010.²⁶⁵

Multiple constructed series of photographs that touch on the theme of sickness. The images in the series *Pre-Existing Condition* (2009–2010) look like the aftermath of a messy surgery or autopsy, but are made from fruit and vegetables, hair and fabric. *Medical Interior* (2005–2007) is a mix of documentary and staged images depicting hospital interiors and constructed spaces; for example, a dollhouse room with a red carpet that has white pills on it forming a pattern. In *Carrying, Dressing, Bandaging* (2010) people are exaggeratedly covered with dressing and bandages. Almanas' works centres on disease and sickness, but also touches on illness; placed in the middle.

7. Phillip Toledano: Days with my Father (book), 2006–2009.²⁶⁶

A documentary series of a personal story that depicts the author's father's final years as he is suffering from a memory disease. Placed closest to illness.

8. Thilde Jenssen: Canaries (book), 2013.²⁶⁷

An artwork about environmental sickness, which the author herself has. The series depicts people who are isolated from society because of their condition. The work is an illness story in conflict with society; placed between illness and sickness.

9. Elinor Carucci: Pain, 2002–2003.²⁶⁸

Documentary photographs depicting of the author's lower back pain; placed nearest to illness.

10. Nancy Borowick: Cancer Family, 2013 – ongoing.²⁶⁹

Documentary black and white photographs that follow the author's parents' lives and deaths with cancer. The intimate and emotional photographs are taken mostly at home. The work is placed closest to illness.

11. Henrik Malmström: On Borrowed Time (book), 2010.²⁷⁰

The work documents the last few months of the author's sister dying from cancer. The grainy and melancholy black and white photographs are shot at the hospital. The work is placed nearest to illness.

²⁶⁵ K P Almanas, author's website, accessed Nov 8, 2016, www.kathrynparkeralmanas.com

²⁶⁶ P Toledano, author's website, accessed Oct 25, 2016, www.mrtoledano.com/days-with-my-father

²⁶⁷ T Jenssen, author's website, accessed Oct 13, 2016, www.thildejensen.com/canaries.html

²⁶⁸ E Carucci, author's website, accessed Oct 25, 2016, www.elinorcarucci.com/pain.php#o

²⁶⁹ N Borowick, author's website for the Cancer Family project, accessed Oct 25, 2016, www.cancerfamilyongoing.com

²⁷⁰ H Malmström, author's website, accessed Oct 25, 2016, www.henrikmalmstrom.com/work/on-borrowed-time

12. Mary Ellen Mark: Ward 81 (book), 1979.²⁷¹

The book *Ward 81* is a documentary work that depicts female patients at a mental institution in the US. As a whole the book (photographs and texts) takes a critical standpoint on how institutions affect people. The work is placed closest to sickness but towards illness.

13. Siân Davey: Looking For Alice (book), 2015.²⁷²

The book consists of documentary photographs of Davey's daughter with Down's Syndrome. The photographs consist of everyday situations, and Davey writes in the introduction of the series that making the project has been foremost a way for her to examine her relationship with the daughter. Placed closest to illness.

14. Ruth Adams: Unremarkable, 2002–2004.²⁷³

The work is a sequence of 350 self-portraits following the author through cancer (Hodgkin's Disease), chemotherapy, radiation and healing. The portraits show mainly the authors face looking directly at the camera. Adams writes that she wanted to make a cancer journey story that ends in life. The work is placed closest to illness.

15. Kerry Mansfield: Aftermath, 2009.²⁷⁴

The series is a systematic sequence of self-portraits depicting the author before, during and after her mastectomy and cancer treatments. The series is shot with a straight flash against a light blue tile wall, and the images shows the author naked from the waist up. The expressions and postures vary, communicating anxiety, sorrow, indifference and defiance. Placed closest to illness towards disease.

16. Natalie Kriwy: 14/09 Tagebuch einer Genesung (book), 2016.²⁷⁵

The book is a detailed photographic diary of the author undergoing breast cancer and a double mastectomy. The self-portraits and documentary images of the author's surroundings are accompanied with diary-like texts. The work is placed nearest to illness towards sickness as it purposefully challenges the stereotypical image of a sick person.

²⁷¹ M E Mark, Mary Ellen Mark Studio and Library, accessed Oct 25, 2016, www.maryellenmark.com

²⁷² S Davey, author's website, accessed Oct 25, 2016, www.siandavey.com/humannature/

²⁷³ R Adams, author's website, accessed Oct 25, 2016, www.ruthadamsphotography.com

²⁷⁴ K Mansfield, author's website, accessed Oct 25, 2016, www.kerrymansfield.com/aftermath

²⁷⁵ N Kriwy, 14/09 Tagebuch einer Genesung at publisher Random House's website, accessed Oct 25, 2016, www.randomhouse.de/Buch/1409-Tagebuch-einer-Genesung/Natalie-Kriwy/Prestel/e497866.rhd#info



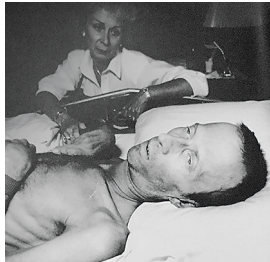
Ruth Adams: *June 1*. From the series *Unremarkable*, 2002–2004.



Mary Ellen Mark: *Ward 81*, Oregon State Hospital, Salem, Oregon, 1976.



Nan Goldin: *Emilia, Brooklyn*, 1994.



Jack Radcliffe: *Pete and a friend*, June 14, 1992.

17. Celine Marchbank: *Tupil*, 2016.²⁷⁶

Documentary images that reflect on the author's experience with her mother, who is diagnosed and treated for lung cancer and a brain tumour, and dies. Many of the photographs are still lifes of flowers. The work depicts the illness experience in a poetic form; closest to illness.

18. *Hospice: A Photographic Inquiry*, 1996.²⁷⁷

Corcoran Gallery of Art and the National Hospice Foundation commissioned five photographers to make work around the theme hospice for an exhibition and a book. Kathy Vargas' works concentrates on death and loss, while Nan Goldin, Jack Radcliffe, Sally Mann and Jim Goldberg's works look at sickness in different ways.

18a. Jim Goldberg

The work depicts Goldberg's father's last days at a hospice care and the father's death. The diary-like colour and black and white photographs are combined with personal letters and descriptions of events and conversations taking place. Placed closest to illness.

18b. Nan Goldin

Goldin's photographs show mostly AIDS patients in New York City. The diary-like photographs are taken at people's homes. Goldin says in the interview introducing the series that she aimed to convey the general experience of being ill and also to face her own mortality. The photo essay is placed closest to illness, towards sickness.

18c. Sally Mann

The black and white photographs, mostly still lifes and sceneries aim to convey the state of being incurably sick, between life and death. The photos include a close up of a dog's snout and two pieces of underwear drying on a line. The photographs are paired with detailed descriptions and stories of the author's experiences with a hospice nurse called Joan and her patients. In the midst of the black and white photographs there is one colour photograph of the author's own father who died from a brain tumour seven years prior. Mann visually examines what matters to the dying people; placed closest to illness towards sickness.

18d. Jack Radcliffe

Radcliffe's photographs are very straightforward black and white photographs depicting hospice patients. The people are photographed

²⁷⁶ C Marchbank, author's website, accessed Oct 25, 2016, www.celinemarchbank.com

²⁷⁷ D Andre, P Brookman, J Livingston (eds.) *Hospice, A Photographic inquiry*. Corcoran Gallery of Art and the National Hospice Foundation. A Bulfinch Press Book, Little Brown and Company, Boston, New York, Toronto, London, 1996.

mostly with their relatives and the photographs are combined with quotes or descriptions of the patients' lives or actions. The photographs, instead of beautifying, show the situations bluntly. The series ends with an unflattering photograph of a dead patient with her eyes half-closed and mouth open. The direct straight-forwardness of the images questions how one should look at the ill, while the texts communicate the experience of being ill. Placed in between sickness and illness, towards the middle.

19. Jennifer Wilkey: *Illness and the Hospital 2005–2009*.²⁷⁸

The author mixes embroidery, various forms of sculpting and photography. *Pills* (2005) presents clusters of different coloured and shaped pills, *Body Studies* (2005) combines photographs of real scars with scar-looking sculptures made of wool, gauze and paper. In the series *Hospital* (2009), Wilkey has added for example organs made with embroidery to a hospital environment and equipment. The series aims to convey how time feels slow while in a hospital. The works as a whole are placed between sickness and disease towards illness.

20. Lauren Greenfield: *Thin (book)*, 2006.²⁷⁹

The book depicts 19 girls and women with eating disorders at Florida Renfrew Center. The project is also a documentary film. The book consists of images depicting everyday life at the Center and portraits combined with first person stories. In addition, the book entails essays by doctors about eating disorders. The work as a whole looks at the illness experience but also the societal structures that have led to the problem; placed between illness and sickness.

21. Sally Mann: *Proud Flesh*, 2003–2009.²⁸⁰

The series is a collection of sensitive black and white photographs of the author's husband, who has late-onset muscular dystrophy. Placed closest to illness.

22. Hannah Wilke: *Intra Venus No. 4, 1992–1993, and other works (1975–1993)*.²⁸¹

Large-scale photographic prints depict the author's own and also her mother's cancer and treatment. The images portray illness experience but also play and question stereotypical representations; placed closest to illness towards sickness.



Jennifer Wilkey: *Red Line*, 2009. (Digital inkjet print / receipt paper and thread.)



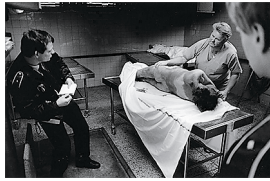
Hannah Wilke: *S.O.S. (Veil)*, 1975.

²⁷⁸ J Wilkey, author's website, accessed Oct 25, 2016, www.jenniferwilkey.com/illness-and-the-hospital/

²⁷⁹ L Greenfield, *Thin*, Chronicle Books, California, 2006.

²⁸⁰ S Mann, author's website, accessed Oct 27, 2016, sallymann.com/selected-works/proud-flesh

²⁸¹ H Wilke, Hannah Wilke collection & archive, accessed Oct 25, 2016, www.hannahwilke.com



Krass Clement, *At Death*, 1990.



Peter Granser: *Portrait 19*, 2001.
From the series *Alzheimer*.

23. Lisa Lindvay: *Hold Together*, 2006 – ongoing.²⁸²

The work depicts the author's siblings and father, who try to physically and emotionally cope with the family's mother's deteriorating mental health. In the photographs the siblings and the father express visually and in a physical form their distress and dilemmas. The mother is not shown. The work is placed nearest to illness.

24. Sohrab Hura: *Life is Elsewhere* (book), 2015.²⁸³

The book is a journal about the author's life, focused on the experience with his mother with acute paranoid schizophrenia. The black and white, grainy and often melancholic images are accompanied with handwritten diary notes. The work is placed nearest to illness.

25. Peter Granser: *Alzheimer* (book), 2015.²⁸⁴

The book is a collection of portraits of Alzheimer's patients. In the series softly lit facial portraits are accompanied with bright milieu portraits of the elderly looking lost. The work looks at the disease from a third-person perspective but also seems to aim at conveying something of the experience of having Alzheimer's Disease; placed between disease and illness.

26. Alejandro Kirchuk: *Never Let You Go*, 2009–2011.²⁸⁵

The photo essay documents the author's grandmother suffering from Alzheimer's and the author's grandfather taking care of his wife. The everyday colour photographs paint a melancholic and loving scene of the couple's life. The work is placed closest to illness.

27. Lydia Flem: *Journal Implicite*, 2013.²⁸⁶

The author, a former writer and psychoanalyst, resorted to photographs when she lost her ability to form words because of a sickness. The photographs are still lifes combining various, often unrelated objects like ginger root, keys and a magnifying glass. The work aims to vocalise Flem's experience without words; placed closest to illness.

28. Krass Clement: *At Death*, 1990.²⁸⁷

The photographs follow the author's mother from the hospital bed to autopsy and cremation, and to the funeral. The black and white documentary photographs depict bluntly the institutional settings and the people working with the dissection and cremation. The work

²⁸² L Lindvay, author's website, accessed Dec 19, 2016, www.lisalindvay.com

²⁸³ S Hura, author's website, accessed Nov 1, 2016, www.sohrabhura.com/Life-is-Elsewhere

²⁸⁴ P Granser, author's website, accessed Nov 1, 2016, granser.de/alzheimer.html

²⁸⁵ A Kirchuk, author's website, accessed Mar 25, 2017, alejandrokirchuk.com

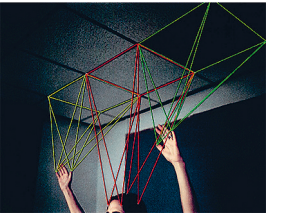
²⁸⁶ L Flem, introduction of Flem's exhibition, Maison Européenne de la photographie, accessed Dec 12, 2017, www.mep-fr.org/evenement/lydia-flem

²⁸⁷ K Clement, author's website, accessed Dec 19, 2016, www.krassclement.com/books/veddoden.html

transforms from an illness story into a depiction of a biological body that is institutionally taken care of; placed in the middle.

29. Maja Daniels & Jill Mueller: *See Me Through This / brca1*, 2012–2014.²⁸⁸

Artist Jill Mueller underwent a preventive surgery for breast cancer, and Maja Daniels documented the medical and physical transformations. The work combines documentary images from Mueller's treatments but also images with added stitch-work on them and, for example, a found bird's nest placed in a tin can. The work examines the illness experience but also looks at the body as a biological entity; placed closest to illness but towards disease.



Maja Daniels & Jill Mueller:
Medical photograph being taken before reconstructive surgery, 2012 (stich-work added 2014).

30. Laia Abril: *The Epilogue*, 2014.²⁸⁹

The author tells the story of the Robinson family, whose daughter Cammy died at the age of 26 from bulimia. The book documents the grief of the family and reconstructs Cammy's life. Placed closest to illness experience.

31. Huub van der Put: *The Mind Is a Muscle* (book), 2012.²⁹⁰

The book chronicles the author's life with terminal illness (Lou Gehrig's disease). The book has two types of images: portraits of the author, taken by other photographers, on the normal pages, and snapshots of his and his family's everyday life inside folded pages which have to be torn open. The division of the images balances between the outside gaze and the personal view on sickness; placed closest to illness towards sickness.

32. Jim Reed: *Working Memory* (book), 2012.²⁹¹

The handmade medical-file looking book combines photographs of an elderly woman, Shirley Jorjorian, suffering from dementia and her surroundings including documents at her home. These photographs are combined with extracts from a test assessing different stages of Dementia. The book presents an outsider view on a dementia patient, but also depicts the absurdity of life without memory; placed between sickness and disease towards illness.

33. Reinier van der Lingen:

***It Could Have Been You If It Hadn't Been Me* (book), 2014.**²⁹²

The book resembles a clinical report. The book shows a sequence of

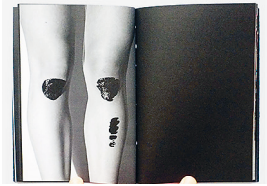
²⁸⁸ M Daniels & J Mueller, Mueller's website, accessed Nov 6, 2016, www.jillmueller.com/now/brca/

²⁸⁹ L Abril, author's website, accessed Oct 27, 2016, www.laiaabril.com/project/the-epilogue/

²⁹⁰ H Van der Put, *The Mind is a Muscle*, The Best Dutch Book Designs, accessed Nov, 6, 2016, www.bestverzorgdeboeken.nl/en/selection/?book_id=326&edition_id=10

²⁹¹ J Reed, *Working memory*, Indie Photobook Library, accessed Nov, 6, 2016, www.indiephotobooklibrary.org/2013/02/working-memory/

²⁹² R Van der Lingen, author's website, accessed Dec 19, 2016, reiniervanderlingen.nl/it-could/



Paschalis Zervas: *To Night. Albedo. Pharmacies*, 2011.



Susanne Otterberg: *No More Junk Mail, Please!*, 2013.

a tightly framed portraits of a woman's face, Babet Boon, who is going through breast cancer, combined with medical data over the course of roughly two years. The work combines illness and disease; placed in between the two.

34. Tatsumi Orimoto: *Art Mama*, (book) 2007.²⁹³

The author has been constructing photographs with his mother suffering from Alzheimer's since the mid 1990s. The playful and staged images include the mother wearing huge cardboard shoes and holding an enormous loaf of bread in her hands. Placed closest to illness, towards sickness as the work observes and communicates the personal experience but also deliberately transforms the illness into performative photographs commenting on culture.

35. Susanne Otterberg: *No More Junk Mail, Please!* (book), 2013.²⁹⁴

The book depicts the author's experience with her grandmother suffering from dementia. The black and white documentary style photographs are sometimes humorous and candid, sometimes blunt; placed closest to illness.

36. Paschalis Zervas: *To Night. Albedo. Pharmacies*. (book) 2011.²⁹⁵

The author combines borrowed and original material to depict a presence of a human illness. Bizarre and poetic book about the feeling of illness. The images include for example a photocopied page of a book that has gone wrong, a black and white image of legs with dark, paint-looking wet circles on the knees; placed closest to illness.

37. Juha Törmälä: *12 Men*, 2015.²⁹⁶

The work is a series of portraits of men with prostate cancer. The work consists of 12 black and white facial portraits of serious-looking men. The series is sponsored by Suomen eturauhassyöpäyhdistys ry and Astellas Pharma. The repeated aesthetics unifies the men into a group that represents a certain type of cancer patient, but because the style of photographs directs the focus to the stoic expressions of the men and because the work is paired with first-person stories of men speaking about disease, the series is placed nearest to illness towards disease.

38. Briony Campbell: *The Dad Project*, 2009.²⁹⁷

The documentary photographs capture the author's experience with her dying father. The images include mourning self-portraits as well as images of the ill father. Placed closest to illness.

39. Max Aguilera-Hellweg:

The Sacred Heart, An Atlas of the Body Seen Through Invasive Surgery, 1997.²⁹⁸

The book depicts invasive surgeries shot with a large format camera. The dark and colourful photographs show people's insides in the operating theatres. The work looks at the body as biomedical object; placed closest to disease.

40. Li Zhaohui: *Specimen – Human Organs Under a Ruler* (book), 2017.²⁹⁹

The work is a series of isolated human organs photographed next to a ruler. The images include for example a fetus, tonsils, a breast and a lung. The photographs are black and white and softly lit. The work is placed closest to disease.

41. Sarah Sundhoff:

At the Hour of Our Death 2010–2011, and *Precious Metal*, 2016.³⁰⁰

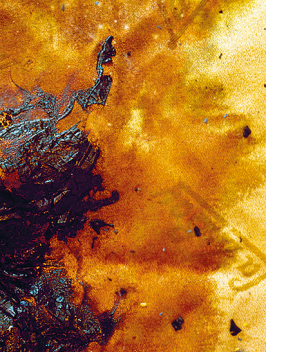
At the Hour of Our Death is a photography series of stains left by dead bodies on different fabrics. The colourful close-ups remind of abstract paintings. *Precious Metal* shows used medical implants that are left after cremation. The work looks at death and repairing of the body from a systematic evidence-based point of view, placed closest to disease, towards sickness.

42. Reiner Riedler: *Will –The Lifesaving Machines* (book), 2017.³⁰¹

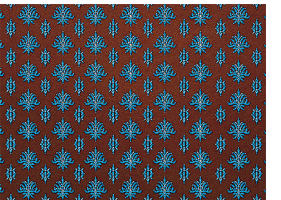
The work is a series of isolated, historical and contemporary medical machines and implants against a black background. The work depicts the institutional and medical machines free of the illness experience; placed between sickness and disease.

43. Tamara Staples: *Side Effects May Include*, 2012–2016.³⁰²

The work consists of assembled images of miniature wallpapers and rooms that Staples has constructed from the pills that her sister, who suffered from bipolar disorder, left behind after taking her own life. The statement criticises the way mental disorders are treated with an excess of



Sarah Sundhoff: *Heart Attack, Male, 50 years old (I)*, 2010. From the series *At the Hour of Our Death*.



Tamara Staples: *Side Effects May Include*, 2012–2016.

293 T Orimoto, introduction of author's works, Gallery DNA, accessed Mar 25, 2017, www.dna-galerie.de/en/artists/tatsumi-orimoto/tatsumi-orimoto-works.php

294 S Otterberg, author's website, accessed Dec 19, 2016, susanneotterberg.carbonmade.com/projects/5759761

295 P Zervas, *To Night. Albedo. Pharmacies*. Josef Chladek on photobooks and books, accessed Dec 19, 2016, josefchladek.com/book/paschalis_zervas_-_to_night_albedo_pharmacies

296 J Törmälä, *12 miestä – tarinoita eturauhassyövästä*, Astellas Pharma, accessed Nov 1, 2016, eturauhastieto.fi/

297 B Campbell, author's website, accessed Mar 25, 2017, www.brionycampbell.com/projects/the-dad-project/

298 M Aguilera-Hellweg, *The sacred heart, an atlas of the body seen through invasive surgery*, Bulfinch Press, Hong Kong, 1997.

299 Li Zhaohui, *Specimen*, Bromide Publishing House Ltd., Hong Kong, 2017.

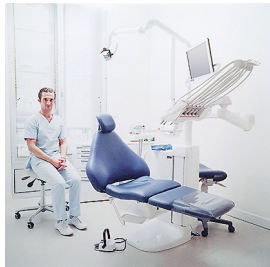
300 S Sundhoff, author's website, accessed Oct 27, 2016, www.sarahsundhoff.com/

301 R Riedler, author's website, accessed Oct 25, 2017, www.photography.at/books_the_lifesaving_machines.html

302 T Staples, author's website, accessed Nov 1, 2016, www.tamarastaples.com/SIDE-EFFECTS-MAY-INCLUDE/thumbs



Stefan Ruiz: *Emergency*, 2008.



Constant An  : *Consultations*, 2008.

medication but also allocates the photographer's own experience with the loss. The ornamental colourful wallpapers made out of pills create a fairy-tale-like atmosphere; placed in the middle.

44. *Clinic*, 2008.³⁰³

French art director R  mi Faucheux curated a documentary art photography book *Clinic* in 2008. The book consists of commissioned works by eleven contemporary photographers. In the book, German Albrecht Kunkel's photographs portray pregnant women before their doctor consultations, and Italian Mario Palmieri's series *The Morgue* looks at the institutional spaces for bodies after death, and the nine other photographers look at sickness in different forms. The book's starting point is the institutional setting of a hospital. All the series are accompanied with short introductions but no titles or other information is provided about the individual works.

44a. Matthew Monteith: *The Hospital*

The works concentrates on the functions of hospitals by documenting hospital equipment and waiting rooms and portraying the medical staff. The photographs show mostly empty and clean spaces. The work is placed closest to sickness towards disease.

44b. Christophe Bourguedieu: *Scenes*

The author accompanied mobile resuscitation units in France and the work depicts landscape-like sceneries of emergencies. The photographs are taken mostly at a distance, on streets, at parks and at people's homes. Only fragments of patients are shown. The work looks at sickness from a distance, through a medical and institutional setting; placed between sickness and disease.

44c. Stefan Ruiz: *Emergency*

The work is a combination of mostly deadpan portraits of medical staff and patients and details of injuries or objects relating to them in the context of emergency situations. In the work, portraits of patients and portraits of doctors/nurses are placed on the same spreads, juxtaposing the differing power positions while the repeated formalism of the photographs equalises them, rendering them essentially indistinguishable; the work is placed nearest to sickness.

44d. Geoffroy de Boismenu: *The Soul and the Machine*

The work shows fragments of bodies in the operating theatres veiled by a blue surgical drape. From the photographs, it is often hard to tell which part of a body is visible. The dark and theatrical photographs lit by an operating room light look at the veiled bodies as still lifes; placed closest to disease.

³⁰³ R Faucheux (ed.), *Clinic*, Images en Manoeuvres Editions, Marseille, 2008.

44e. Olivier Amsellem: *Long Stay Hospitals. A Time Space*

The clean and broad landscape photographs capture old health centres and sanatoriums built 1930–1970s. The work looks at sickness through neutral, cleanly photographed buildings; placed closest to sickness.

44f. Constant An  : *Consultations*

The work is a collection of systemic milieu portraits of doctors and specialists. All the subjects are photographed both in their medical offices and in their consultation rooms, and the images are shown side by side. The deadpan portraits show the mundaneness of their occupations. The work takes a medical point of view to sickness through the institutional setting; placed between sickness and disease.

44g. Ville Lenkkeri: *Cases of Curiosity*

The photographic work depicts defective human symptoms that at one point had aroused pity, and now have become collectibles and medical oddities. The images show anatomical samples, skeletons and instructional models. The work looks at disease through culture; placed closest to disease but towards sickness.

44h. Eric Baudelaire: *Pavillon Gabriel*

The work functions as a diptych, where one page documents people's dialysis treatments and the other follows a kidney donation from mother to daughter. The work is distanced and clean. Even with the exception of three portraits the work straightforwardly follows a medical procedure; placed closest to disease towards sickness.

44i. Jacqueline Hassink: *The Paimio Sanatorium: An Interpretation*

The series is a collection of interior and exterior photographs of the Paimio Sanatorium designed by Alvar Aalto. All the photographs are without people. The hospital was built for tuberculosis patients and now specialises in long-term diseases. The work looks at disease from an institutional and historical point of view; placed closest to sickness.

45. Sami Parkkinen: *Paradise*, 2010.³⁰⁴

The series expresses the author's world with severe depression and recovering from it. The work consists of mostly surreal still life images. Placed closest to illness as the series aims to voice the personal experience of being depressed.

46. Akseli Valmunen: *3Hz–300GHz*, 2015.³⁰⁵

The work depicts people who are sensitive to radiation (Wi-Fi, mobile phones and telecom towers). The series is a collection of milieu portraits,



Ville Lenkkeri: *Cases of Curiosity*, 2008.



Sami Parkkinen: *Self portrait as a fruit*, 2010. From the series *Paradise*.

³⁰⁴ S Parkkinen, author's website, accessed Mar 25, 2017, www.samiparkkinen.com

³⁰⁵ A Valmunen, author's website, accessed Mar 25, 2017, akselivalmunen.com/3Hz-300GHz



Toni Kitti: *Strike a Pose*, 2013.
From the series *The Persistence of Plastic*.

images of rooms, landscapes and equipment. Placed between disease and sickness as the series remains at a distant from the personal illness experience and concentrates on showing not just the affected people but also the possible causes and protective equipment.

47. Leena Louhivaara: Saa katsoa, 2008.³⁰⁶

The work consists of black and white portraits of 12 women of different ages with breast cancer. The images are accompanied with quotes from the people photographed and the artist statement contemplates how one is supposed to look at them. The work is placed closest to illness towards sickness as it tries to encapsulate what it is to have breast cancer but also negotiates how one is allowed to look at women with breast cancer.

48. Meeri Koutaniemi: Oasis, 2013.³⁰⁷

The documentary work features four transsexual men with HIV or AIDS living at a shelter in Mexico. The photographs are accompanied with in-depth interviews. The series is placed closest to illness as it concentrates on voicing the individual life experiences.

49. Miikka Pirinen: The Rare, 2013.³⁰⁸

The work is a collection of portraits of children and teenagers with a statistically rare disease, such as Netherton syndrome. It is a documentary collection of well-lit, often full-body milieu portraits shot at homes. Placed between illness and disease.

50. Toni Kitti: The Persistence of Plastic, 2013–2016.³⁰⁹

The work is a collection of plastic objects and self-portraits. Kitti writes that he loves plastic, because it does not decay like him. Kitti was diagnosed with AIDS in 2012. In a self-portrait titled *Strike a Pose*, Kitti, having AIDS, looks at the camera with a wide smile, his naked upper body full with Kaposi's sarcoma lesions. Kitti's hands are covering his chest and crotch. Placed closest to illness as it conveys Kitti's personal love with plastic but towards sickness as parts of the work can be seen to question the suffering position of the sick.

51. Max Kandhola: Illustration of Life (book), 2002.³¹⁰

The work documents the author's father with cancer and dying from it. The images include extreme close-ups of hair, bruises and eyes. Despite the fact that some of the photographs seem detached and clinically observant,

³⁰⁶ L Louhivaara, *Saa katsoa*, Kuva & Coaching Oy, accessed Mar 25, 2017, www.omakuvaminakuva.fi/sivut/saa_katsoa/

³⁰⁷ M Koutaniemi, *Oasis*, Lens Culture, accessed Mar 25, 2017, www.lensculture.com/projects/34370-oasis

³⁰⁸ M Pirinen, author's website, accessed Mar 25, 2017, www.miikkapirinen.com/#/rare/

³⁰⁹ T Kitti, author's website, accessed Sep 25, 2017, www.tonikitti.com/index.php?art/the-persistence-of-plastic/

³¹⁰ M Kandhola, *Illustration of Life*, Light Work, Syracuse, 2002

the work as a whole negotiates the author's experience with his father's illness and death; placed closest to illness.

52. Mark Morrisroe: 1988–89.³¹¹

Morrisroe died of AIDS and his late photographs include lung x-rays where Morrisroe has added colour, and eroticised nude or half-nude portraits of him in a hospital bed. Morrisroe literally strikes poses and meets the viewer's gaze while the shown body is consumed by the disease. The work is placed between sickness and illness as despite being a personal illness, Morrisroe is questioning the "right" way of being ill.

53. Koji Takiguchi: Sou (Book), 2014.³¹²

The book portrays the author's mother-in-law dying from cancer and the father-in-law's sudden illness and death around the time of the birth of the author's child. The book covers a personal story; placed nearest to illness.

54. Maija Tammi: Removals, 2011–2013.³¹³

A series of the most common Western diseases showing only the removed parts: cancers, goitres and gallstones. The photographs are taken in the operating rooms, lit with the operating room light. The removed parts are placed in clean emesis basins. In the book *Leftover/Removals* (2014) the images are accompanied with transcribed conversations of three surgeons, who are looking at the photographs and discussing what might be depicted and the aesthetics of the photos. The work is placed closest to disease.

55. Maija Tammi: Leftover, 2014.³¹⁴

Photographs of, and a sculpture comprised of used radiation therapy masks worn by an anonymous model. The artist statement is a hypothetical dialogue with an imaginary cancer that comments on the cultural, sometimes misguided, views on cancer. The work centres on the institutional way of dealing with sickness but at the same time shows traces of disease; placed between sickness and disease.

56. Maija Tammi: White Rabbit Fever, 2015–2016.³¹⁵

The work traces sickness in relation to life and death and contemplates the possibility of immortal life in the form of forever-growing cancer cell lines. The work includes a sequence of a decaying rabbit corpse and a sequence of HeLa cells growing inside a cell culture bottle. Also, a selection of creature-looking cancer cells of the Pa-Ju and Us-Ki cell lines are shown

³¹¹ M Morrisroe, artist introduction, Clamp Art, accessed Sep 25, 2017, clampart.com/2012/02/mark-morrisroe-1959-1989/#/5

³¹² K Takiguchi, author's website, accessed Sep 25, 2017, www.kojitaki.com/sou

³¹³ M Tammi, *Leftover/Removals*, Kehrer Verlag, Heidelberg, 2014.

³¹⁴ M Tammi, *Leftover/Removals*, Kehrer Verlag, Heidelberg, 2014.

³¹⁵ M Tammi, *White Rabbit Fever*, Bromide Books, Hong Kong, 2017.



Koji Takiguchi: *Sou*, 2014.



Nancy Borowick: *Cancer Family, Part 1, together*, 2013 – ongoing.



Sally Mann: *Proud Flesh*, 2003–2009.

inside of installation boxes. The works look at sickness in general, from a philosophical but still tangible point of view; placed closest to sickness, towards disease.

3.4.1. A concentration on illness

The biggest concentration of the artworks is at the illness corner; 32 artworks of the total 67 are closer to illness than sickness and disease, indicating that most photographic artworks on the theme express the experience of being ill or being close to someone who is ill. Eight of the artworks are closest to the disease corner, and nine are closest to sickness. In the centre of the diagram there are three artworks. All the other artworks are in between two or three different aspects.

Out of these 32 artworks close to illness, 10 are about the author's own illness, 14 are about a close family member's illness, and the rest are about the illness experience but without the photographer, a friend or family member being ill. One example of the works at the illness corner is Nancy Borowick's *Cancer Family* (2013 – ongoing). The documentary series depicts the author's parents' managing cancer and dying from it. This series of black and white photographs show everyday life situations concentrating on the parents' relationship with each other. The series narrates a personal story.

Another example at the illness corner is Sally Mann's *Proud Flesh* (2003–2009). The series of wet collodion images depict the body of her husband Larry, who has late-onset muscular dystrophy. The series is a sensual and melancholic portrayal of a weakening body. It also encapsulates Mann's own feelings toward her husband:

'The gods might reasonably have slapped this particular lantern out of my raised hand, for before me lay a man as naked and vulnerable as any wretch strung across the mythical, vulture-topped rock. At our ages, we are past the prime of life, given to sinew and sag, and Larry bears, with his trademark god-like nobility, the further affliction of a late-onset muscular dystrophy. That he was so willing is both heartbreaking and terrifying at once.'³¹⁶

The works about personal illnesses can also be called autopathographies, a term coined by researcher Thomas Couser. The term refers to the

³¹⁶ Sally Mann interviewed by Joerg Colberg at Conscientious blog on Aug 19, 2009, accessed March 25, 2017, jmcberg.com/weblog/2009/08/sally_mann_proud_flesh/

situation where one's life narrative is disrupted by a bodily dysfunction and the borders of identity have to be negotiated again.³¹⁷ This disruption is evident in photographer Kerry Mansfield's statement of *Aftermath*:

'Needless to say it came as quite a shock. I had exercised and eaten correctly, and like many of my age, I felt indestructible, never thinking the most basic of dwellings could be lost. Faced with the nihilistic process of radical chemotherapy and surgery, my ideas of "where" I exist turned inward. As the doctors, with their knives and chemistry broke down the physical structure in which I lived, the relationship between the cellular self and the metaphysical self became glaringly clear.'³¹⁸



Kerry Mansfield: *Aftermath*, 2009.

Mansfield's work is a series of self-portraits before, during and after her mastectomy and cancer treatments.

Pardo and Morcate, who have studied autobiographical art photographs about terminal illnesses, differentiate between three different ways in which photographers visualise the theme: paying homage to the patient, expressing their own grief towards the ill person and negotiating their own relationship with mortality.³¹⁹ In my diagram, most autobiographical stories are located at the illness corner, but the aspect that most often affects the position of the work more toward sickness or disease or both, is Pardo and Morcate's third aspect; how the artist negotiates her of his own relationship with malady and mortality. In terms of the diagram, the decisive factor is whether the artist's main view remains strictly personal or if she or he tries to convey a bigger point of view. For example, Jo Spence criticises the object-role offered to the sick person by asking whose property her breasts are and by questioning the 'right' and 'wrong' way of being ill.

Despite the majority of the personal works (works which are based on the author or the author's relatives) being placed in the illness corner, not all are. One exception is Krass Clement's book *At Death*, made in 1990. The work starts with the illness experience, with the author's mother in a hospital bed, but then transforms into an institutional depiction of the autopsy and cremation. The photographs show the personnel at work in their everyday tasks, and the mother turns into a sort of an object, which is gazed from a distance. In my view, the book combines the illness experience (of the photographer), the institutional procedures and the objective biomedical gaze.

³¹⁷ H Thomas (ed.), *Malady and mortality. Illness, disease and death in literary and visual culture*, Cambridge Scholars Publishing, Newcastle, 2016, p. 4.

³¹⁸ Kerry Mansfield's website, accessed Nov 25, 2016, www.kerrymansfield.com/aftermath/

³¹⁹ R Pardo, M Morcate, 'Grief, illness and death in contemporary photography' in *Malady and mortality. Illness, disease and death in literary and visual culture*, Newcastle, Cambridge Scholars Publishing, p. 245–251, 2016, p. 248.



David Maisel: *Library of Dust* (Asylum 1), 2006.



Max Aguilera-Hellweg: *Scalp, gauze and hair*, in *The Sacred Heart*, 1997.

The clearest examples of sickness, illness and disease, are placed at the tips of the corners in the diagram. One work close to the top of the triangle, at sickness, is David Maisel's *Asylum* (2006)³²⁰, which is a series of photographs of old, empty asylum rooms and corridors. The photographs have faint traces of medical procedures that were once conducted in the space, but mostly the series depicts dilapidated walls and ceilings. The photographs are taken using the available light in the different spaces, and they show decaying spaces through the walls, corners and ceilings, and a few details on the floors. The photographs are balanced in their composition and minimalistic also in their content. The series offers no link to a specific illness experience or experiences, rather the photographs comprise a collective remembrance or evidence of how mental illnesses have been institutionally treated and cared for. It is the style of the photographs, emptiness of the spaces and the decay of the building that build up a sort of nonexistence of a disease.

Disease is clearly presented in Max Aguilera-Hellweg's *The Sacred Heart* (1997). The work depicts the diseased or broken body opened up and photographed as still life. The work resembles a guidebook on surgical procedures (there are also small sequences) or a taxonomical depiction of exotic animals, as it is sometimes hard to recognise what part of a person is in the photograph. In Aguilera-Hellweg's book the human bodies and the parts of human bodies are presented as objects. Similarly to Dallaporta's images, the subjects are in the midst of darkness, in the centre of the images so the viewer's gaze is directed straight to the light in the middle. The wide depth of field and large format of the images reveal a great deal of details and structures. The vivid colours also add to the feel of proximity, as one can see the bodily fluids and surfaces of internal organs so clearly. Many of the images in the book are difficult to look at; they are can be seen to be abject, something that I will examine more closely in Chapter Five.

One formal feature that is more prevalent in the works closest to disease than in the others is an index-like method, meaning that the work is a repetitive series of photographs that are taken against a similar background, often from the same distance, lit similarly and also feature objects of a similar theme. Examples of this method are Aguilera-Hellweg's open surgeries, Dallaporta's *Fragile*, Li Zhaohui's *Human Organs Under a Ruler*, and Reiner Riedler's *Will – The Lifesaving Machines*. Thus, this approach is also one of the factors that make the works appear more objective-like, more statistical, more biomedical, leading me to place them closest to disease.

320 Images from the *Asylum* series are included in Maisel's book *Library of Dust* (2008), which also entails photographs of metal canisters containing ashes of deceased psychiatric patients, and details of these cans and found objects. The isolated images of canisters would as their own series be placed closest to disease, but towards sickness in the diagram.

The formal analysis of the artworks in the diagram reveals that 40 are about life-threatening sicknesses, mostly cancers (16). There are no works about the common cold, stomach flu, rash or headache. It can be that these conditions are seen mostly as nuisances. As medical historian Henry E. Sigerist writes, all primitive tribes know about diseases that require no explanation, and are not even counted as sicknesses as everyone has them.³²¹

Out of the 16 works on cancer that are included in the diagram, half are breast cancer. Most of these works are autopathographies (7) with the exception of Leena Louhivaara's series with various women with breast cancer. What is visually common to almost all the breast cancer works is that the actual breasts are shown. Works by Jo Spence, Hannah Wilke, Kerry Mansfield and Natalie Kriwy, and Leena Louhivaara all show the physical transformation of the breasts. The missing and reconstructed breasts are shown and examined and looked at in the photographs. In works about breast cancer, the body plays a central role, even though the approaches vary.

Jo Spence's work is defiant and political; she for example places a breast implant on a frying pan and constructs posters of the experience that mimic the style of yellow press. Natalie Kriwy's book is humorous and gentle; she makes photographs for example with her head in various states of baldness, smiles in a multitude of the images, and her photographs are brightly lit and clean. Kerry Mansfield's work on the other hand is laconic; only the positions of the body and the expression change in the photographs taken with a straight flash against a blue tile wall. While Spence is holding a 'booby prize' next to her disfigured breast in a photograph, Kriwy has for example painted her breasts as colourful eyes, and Mansfield just looks at the bare breast. All the works except Leena Louhivaara's work are in colour. When looking at sex-specific cancers, there is also one work depicting prostate cancer. Juha Törmälä's *12 Men* is a series of stoic black and white portraits of very serious looking, fully clothed men.

Another recurring theme in the artworks is dementia or Alzheimer's, which is depicted in 6 works. The approaches vary from illness stories to more distanced, systematised and poetic approaches; Jim Reed's indie book presents the absurdity of life without memory, Tatsumi Orimoto has transformed her mother into an *Art Mama* and performs in photographs with her. In Phillip Toledano's *Days with My Father*, the father poses with two cookies on top of his chest like nipples, and also Susanne Otterberg's *No More Junk Mail, Please!* plays with the candid postures and expressions of her grandmother. When comparing all the works depicting dementia and

321 H E Sigerist, *A history of medicine, Volume 1, Primitive and archaic medicine*, Oxford University Press, New York and Oxford, 1987, p. 125–126.



Natalie Kriwy: *14/09 Tagebuch einer Genesung*, 2016.



Jo Spence and Dr Tim Sheard, *Narratives of Dis-ease (Expunged)*, 1990.



Tatsumi Orimoto, *Breadman Son + Alzheimer Mama*, 1996/2007.



Lisa Lindvay: *Hold Together*, 2006 – ongoing.

Alzheimer's to all the works of cancer, the first group seems to be lighter and more playful in their approaches than the ones depicting cancer, Natalie Kriwy's work being the exception. In the dementia stories, life seems more absurd and photographers also construct and stage images, whereas in cancer stories photographers follow and document what is happening.

Children seem not to be sick. In the artworks that show the sick person (42), the sick person is an adult woman in 18 of the artworks, an adult man in 11 of them, and 10 works depict both genders. There are three exceptions: Siân Davey's *Looking for Alice* depicts the author's daughter with Down's Syndrome, Miikka Pirinen portrays children and adolescents with rare diseases, and Lauren Greenfield's subjects are teenagers.

Despite the many autopathographies and photo essays of the ill, there is a canon of works that do not show the sick but rather parts of them (Aguilera-Hellweg), or medical machines (Riedler), institutions and the people working in them (Ruiz, Monteith). As this research looks at human sickness, which is most often seen as being located in the diseased body, most of the artworks that do not show actual ill people, still show parts of bodies, or places and traces of where the bodies are examined, held, cured, cut or processed. However, there are exceptions that aim to capture the illness experience in a more abstract way, such as Sally Mann's work in the *Hospice* book. Mann's series of photographs show for example a snout of a dog, the ocean, a little statue in a garden, and a fallen bridge, as she is trying to document the things that matter to a dying person.

Another interesting example is Lisa Lindvay's *Hold Together* (2006–ongoing) in which the mother, who is suffering from mental problems, is not shown at all and neither are any of her private things. What is shown instead, are the father and the siblings expressing visually, and metaphorically, their experience with the mother. The photographs have a documentary feel with a theatrical intensity; for example, in one of her photographs the dad is standing in a flower pot, in another a brother is laying on a bed without mattress, with numerous soda bottles protruding from underneath, and in one photograph doughnuts are placed into a smiling half circle on a pillow. Lindvay uses diffused natural light that contributes to the documentary feel.

The majority, 44 works from the 67, are plainly documentary, meaning that they depict real ill people, places, machines or details without bringing in additional meanings by purposefully staging or constructing (lighting choices are excluded). The other works mix documentary with added or staged elements or are completely constructed. Documentary images pervade all three aspects of the diagram; illness-works are often photography essays of actually sick people, disease-works show real

surgeries and machines, and sickness-works authentic doctors and institutions. One of the exceptions to the documentary canon is Tamara Staples' *Side Effects May Include* (2012–2016). The images are constructed from medical pills the author's sister left behind after taking her own life. The pills are used to form ornament-like wallpaper patterns and a pattern for a dress.

Another exception is Kathryn Parker Almanas in her various works, which take advantage of what people expect to see. Her photographs look like medical procedures or like the aftermath of an accident or a surgery, but the images are constructed photographs of dissected fruit, various organic matter and fabric. Almanas' work *Carrying, Dressing, Bandaging* overly exaggerates bandaging on people in various ways, and *Medical Interior* oscillates between apparently documentary real and constructed images. The series are not accompanied by introductory texts or artist statements. In the diagram, Almanas' works are placed in the middle because as a whole they can be interpreted as belonging to all three categories equally.

The anthology *Clinic* (2008) – taken as a whole rather than by the individual works – could have been placed between sickness and disease as all the works in the book are scattered between the two; not even one of the works address the illness experience. The book is a deliberate effort to see beyond emotions as Michel Poivert writes in the introduction:

'It [the book] is also documentary in form, where every subject represents a profound study on distance, challenging the emotion that all too often dominates the image of the world of illness, and hospitals in general.'³²²

The book is a well-needed perspective among the artworks in the diagram.

The majority of the works in the diagram has been made in the last twenty years. Thus, when looking at the artworks from before 2000s in the diagram, such as by Spence, Wilke, Morrisroe, Clement and Mark, they are all closer to sickness than the other works on average. These works seem to be more critical about medicine, institutional structures and cultural gaze when compared to the majority of the contemporary works that don't have the same defiant attitude.

Despite the 'critical' works being nearest to sickness, all three aspects – sickness, disease and illness – take part, as representations, in creating, affirming and reconstructing the ways to be sick and experience sickness. The diagram's own value is in the way it teases out differences in how the works communicate private and public, objective and subjective, specific and general.

³²² M Poivert 'Clinic' in *Clinic*, Images en Manoeuvres Editions, Marseille, 2008, p. 4.



Kathryn Parker Almanas: *Pre-Existing Condition*, 2009–2010.



Kathryn Parker Almanas: *Carrying, Dressing, Bandaging*, 2010.

A majority of the artworks in the diagram consist of several photographs; they are most often either conceptual series, photoessays or photoreportages. In many illness stories the individual photographs are bound together by a narrative, passage of time, for example from illness to death as in Nancy Borowicks's and Krass Clement's works. Many sickness works have unified camera angles and lighting choices as for example in Olivier Amsellem's work, whereas many disease works are even more visually repetitive, such as Dallaporta's *Fragile*.

However it should be noted that photography festivals (for example Les Recontres d'Arles), photographic competitions (for example FOAM Talent), and photography book awards ask for and show 'photography series' instead of individual photographs. Seriality can be seen to be ingrained in the photography industry's current practices.

I acknowledge that the diagram is not without problems. There are some works that I have not been able to place into it with sufficient accuracy. Interpreting how much an artwork is about social norms or medicalisation or power structure, or how much about the illness experience and how much about disease as a biomedical model, is not always clear. An example is Jennifer Wilkey's works, which present pills photographed in an orderly fashion, hospital rooms with embroidery and constructed scars. In her statement she writes that she hopes to capture the feeling of time passing while at a hospital. I have placed her work in between sickness and disease, towards illness, close to the middle.

Furthermore, all the artworks in the diagram are self-identified series meaning that the starting point has already been that they have had a will to communicate something about sickness in their works or the context of sickness is evident. This means that the diagram cannot negotiate the health-sickness division, as it is already positioned to sickness.

In addition, while many works at first glance seemed to be clearly about one aspect, for example illness, after a more detailed examination, they were then re-positioned towards other aspects or altogether differently on the diagram. Also, analysing the works often changed the interpretation of a similar artwork, as the works are placed in relation to each other. For example David Maisel's *Asylum* (2006) is closer to sickness than Neil Pardington's *The Clinic* (2003–2005) although both show empty institutional rooms. However, Maisel's work reeks of history, and the way the decaying walls are romantically shot seems to draw it away from an objective medical gaze. Whereas Pardington's images of empty hospital rooms, mainly operating theatres, are more contemporary, more blatant, more informative compared to Maisel's. Neither of the works have an introductory text online.

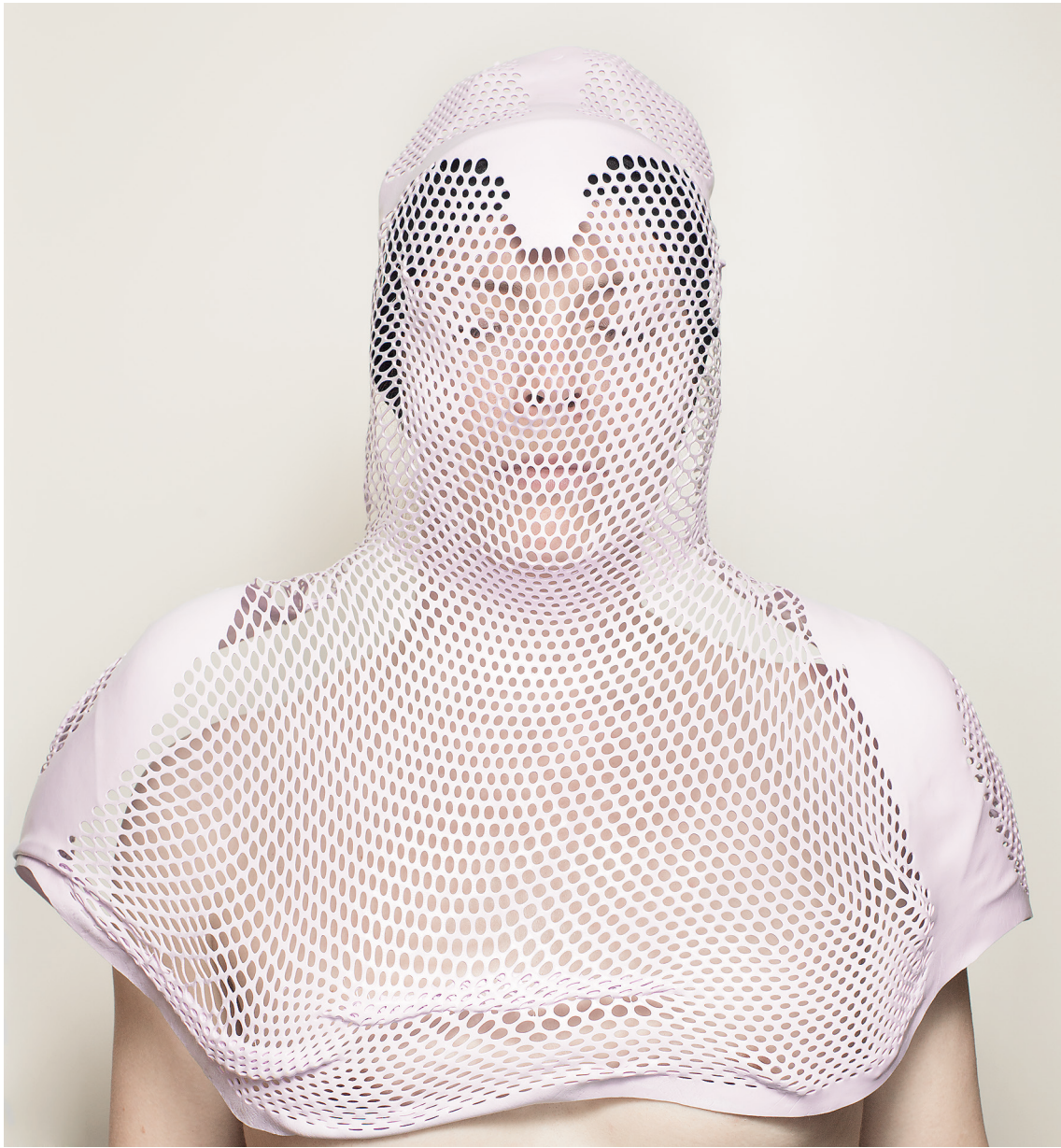
Furthermore, while the diagram concentrates on art photography, the border between photojournalism and art can be especially tricky as in the case of Mary Ellen Mark's *Ward 81*, made in 1975, which depicts female patients at a mental institution in the US. The photographs are documentary and Mark was best known as a photojournalist, but she did deliberately go back to the institution to make a book after she had visited the institution during an assignment, thus indicating that Mark had her own agenda and freedom in the way of depicting the ward. The question between photojournalism and art is further complicated by the fact that many of the works in the diagram are documentary in their nature and many artists also work as photojournalists and vice versa. I have made the decision about whether work has artistic purposes on the basis of the context of the work and whether the author has had solo exhibitions or a significant number of group exhibitions or published art books.

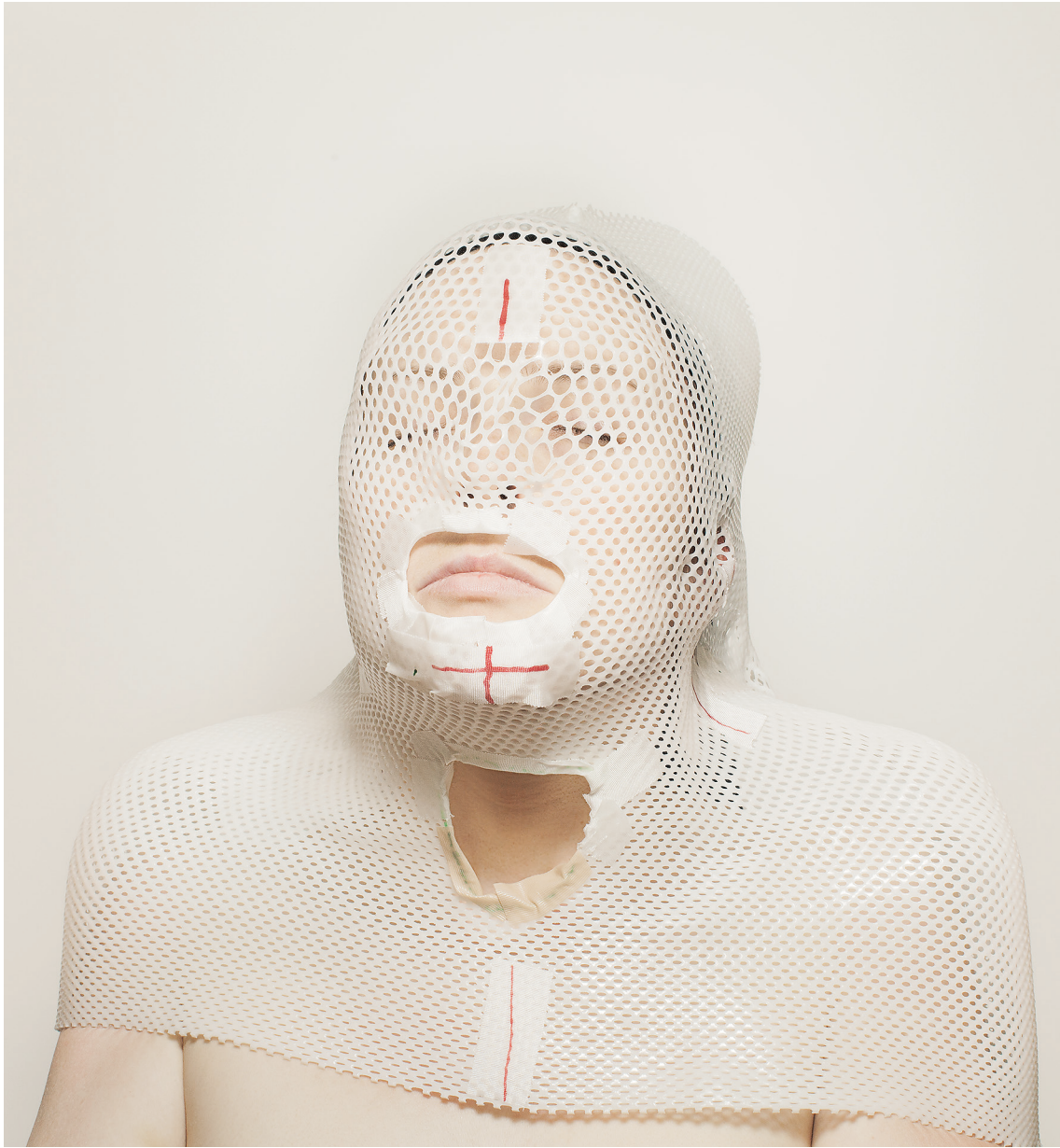
The diagram can be criticised according to the same principles as phenomenologists criticise the disease–illness model: that it separates the experience of illness, being in the world, from the two other aspects (disease and sickness). In addition, it might seem as though the diagram is making a separation between 'subjective' and 'objective' representations (illness and disease). However, photographic artworks are inherently subjective, and the 'objective' in this case is objective-like, made of visual and literal choices that emphasise presenting the world as it is although already permeated by culture and modified by the artists' aesthetic choices. Moreover, the diagram only gives an overview on Western contemporary artworks that does not necessarily apply elsewhere.

As diagrams always are, this diagram is subjective. I have made the terms for inclusion, as well as generated the selection of the works, based not only on what does or does not depict sickness, but also for example on what art photography and photojournalism are and are not. I tested the model at a doctoral seminar at Aalto University, School of Arts, Design and Architecture on March 16, 2017. Nine fellow doctoral students placed three or more artworks from the list into the model. The interpretations of the fellow doctoral candidates landed in the same regions in the diagram as my own placements.





















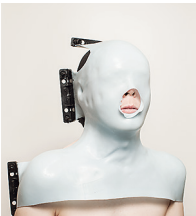
Untitled #1, 2014.
From the series *Leftover*.
Archival pigment print, 60 × 65 cm.



Untitled #7, 2014.
Archival pigment print, 60 × 65 cm.



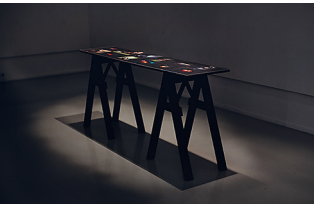
Unlimited Number of Cell Divisions, 2014.
Thermoplastic. Used radiation therapy masks. 180 × 180 × 195 cm.
Photograph by Marc Goodwin at Photographic Gallery Hippolyte in Helsinki, Finland, January 2014.



Untitled #2, 2014.
Archival pigment print, 60 × 65 cm.



Untitled #8, 2014.
Archival pigment print, 60 × 65 cm.



Removals installation, 2015.
Archival pigment prints, table, acrylic glass.
Photographic Centre Peri in Turku, Finland, 2015.



Untitled #3, 2014.
Archival pigment print, 60 × 65 cm.



Untitled #9, 2014.
Archival pigment print, 60 × 65 cm.



Untitled #4, 2014.
Archival pigment print, 60 × 65 cm.



Untitled #10, 2014.
Archival pigment print, 60 × 65 cm.



Untitled #5, 2014.
Archival pigment print, 110 × 120 cm.



Untitled #11, 2014.
Archival pigment print, 60 × 65 cm.



Untitled #6, 2014.
Archival pigment print, 110 × 120 cm.

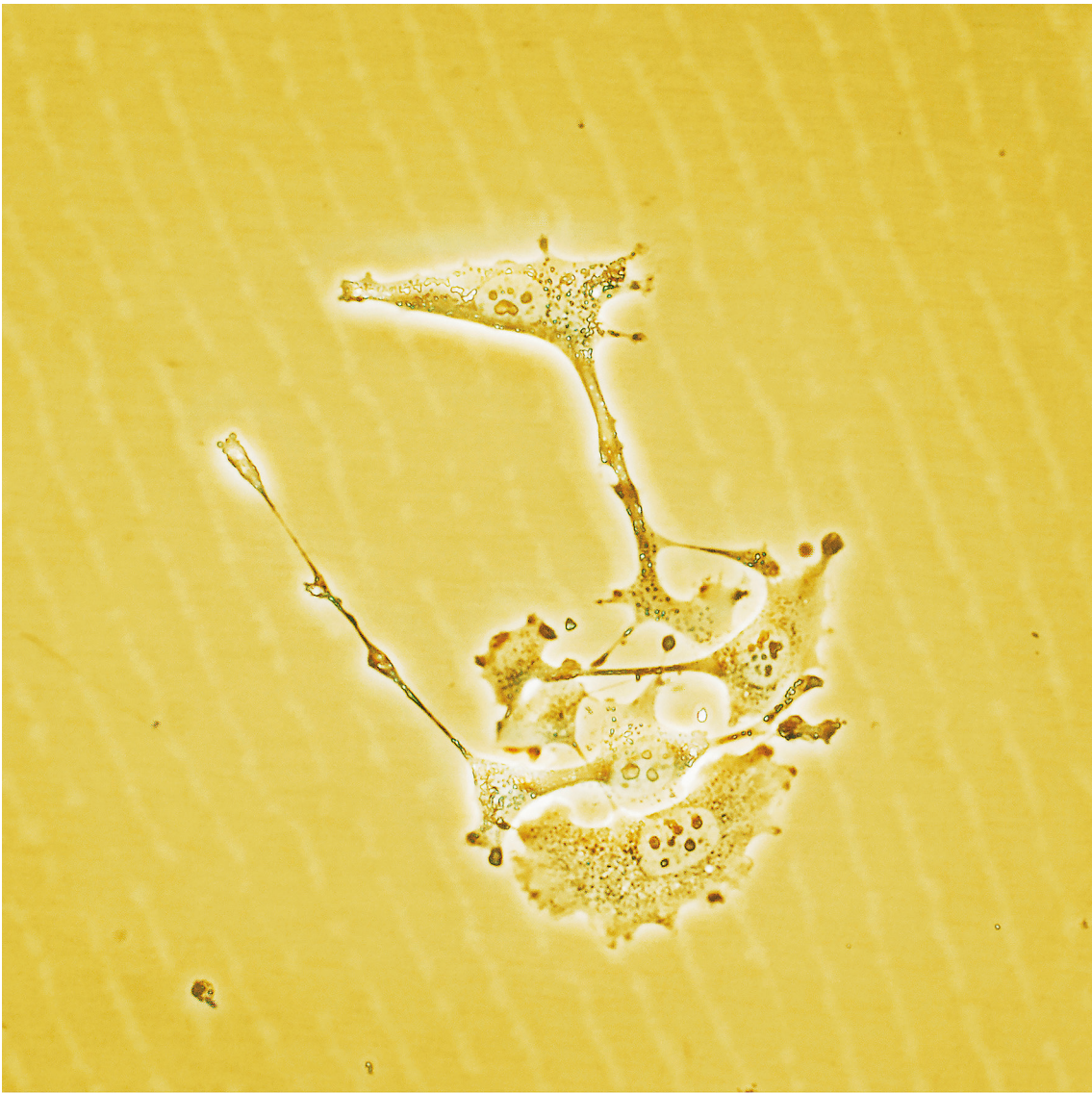


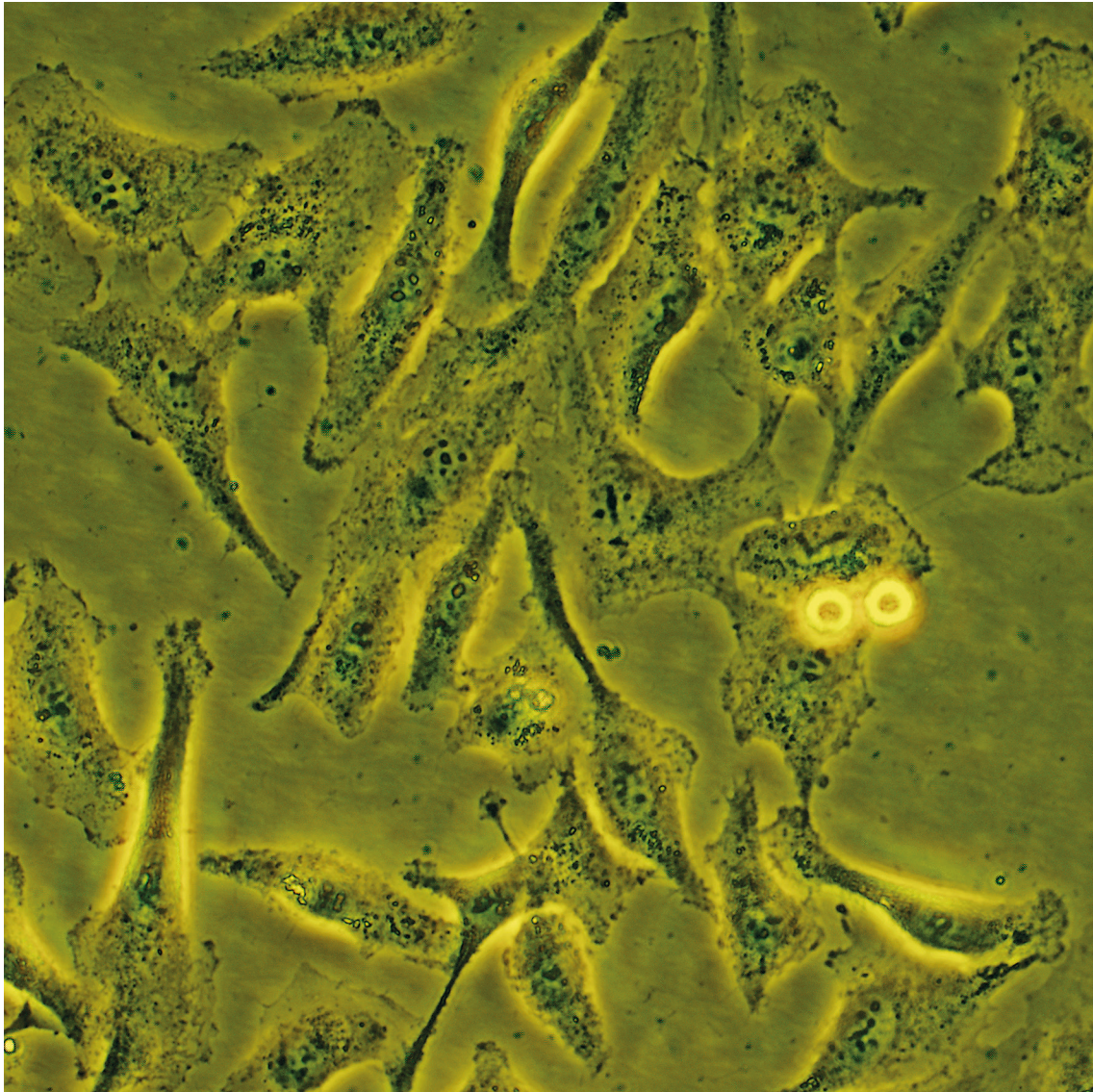
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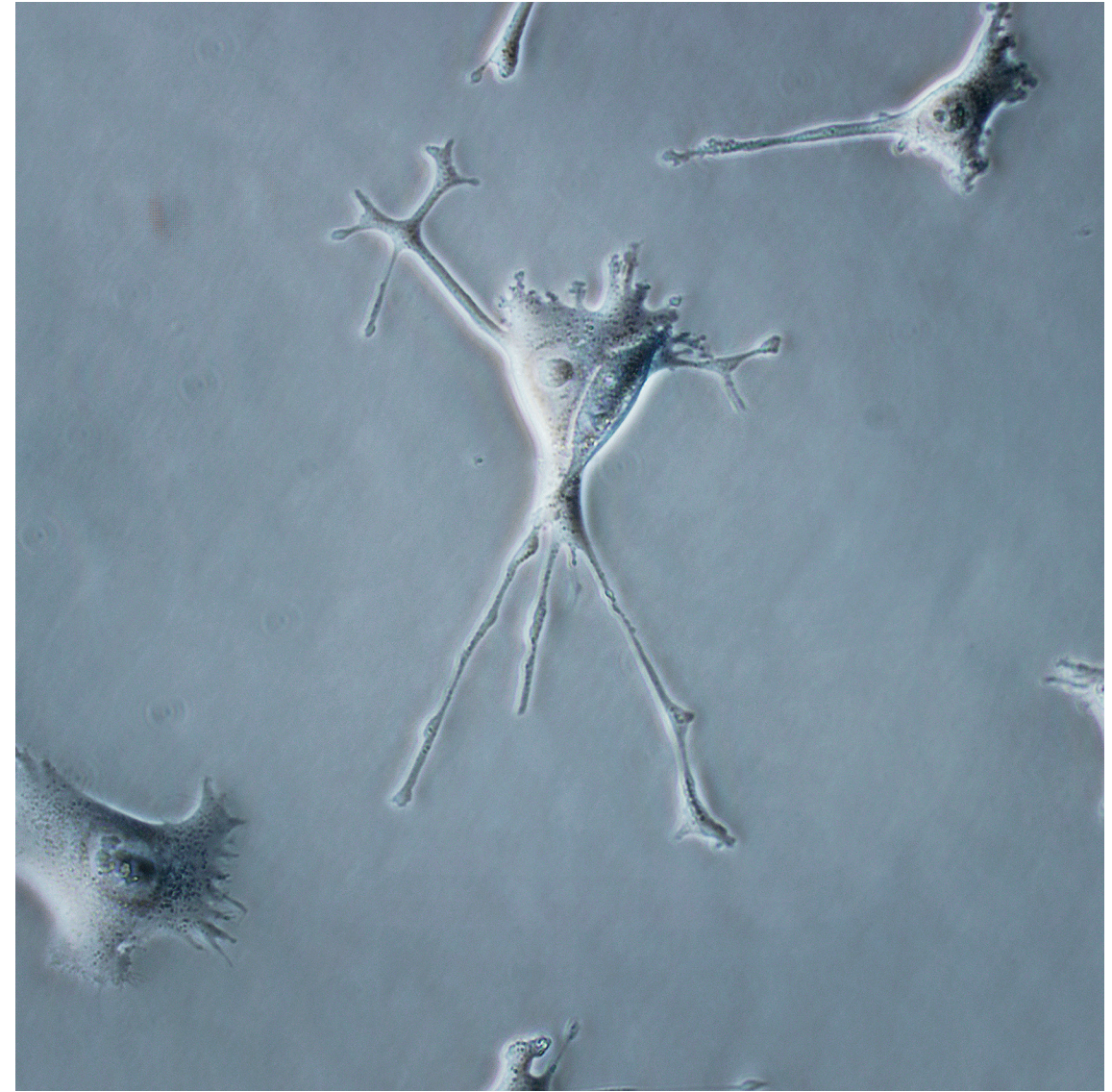
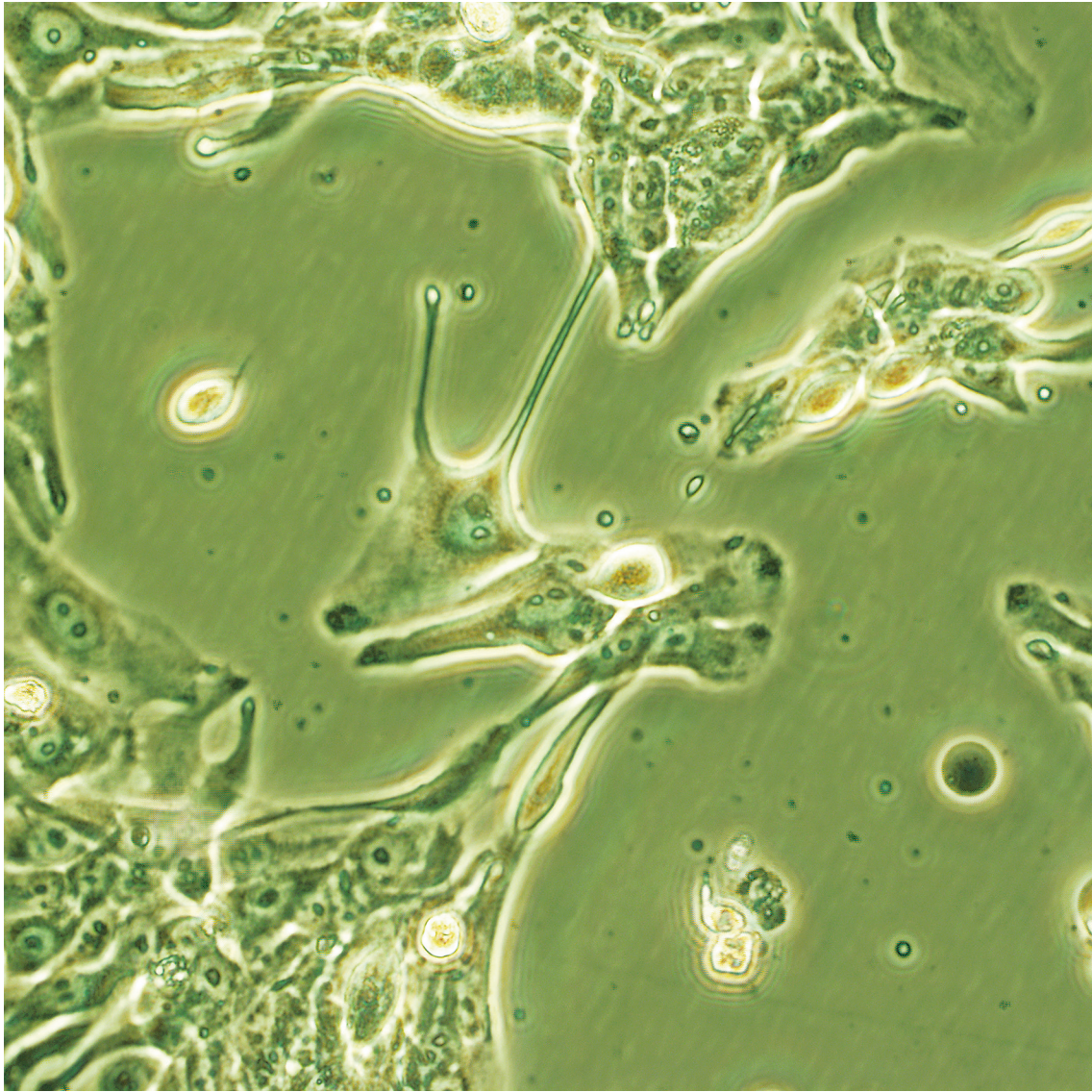
















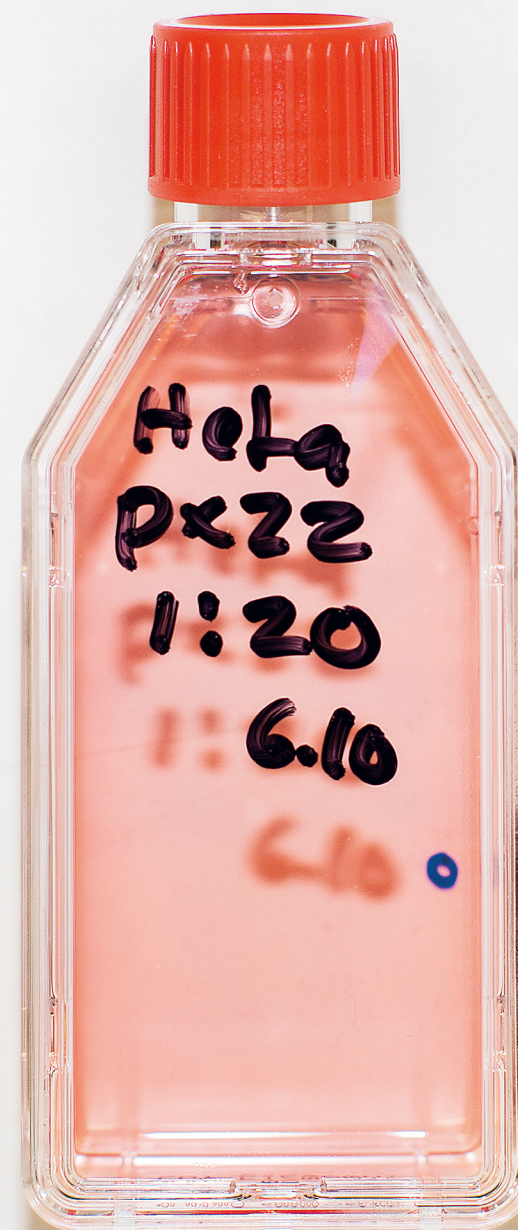


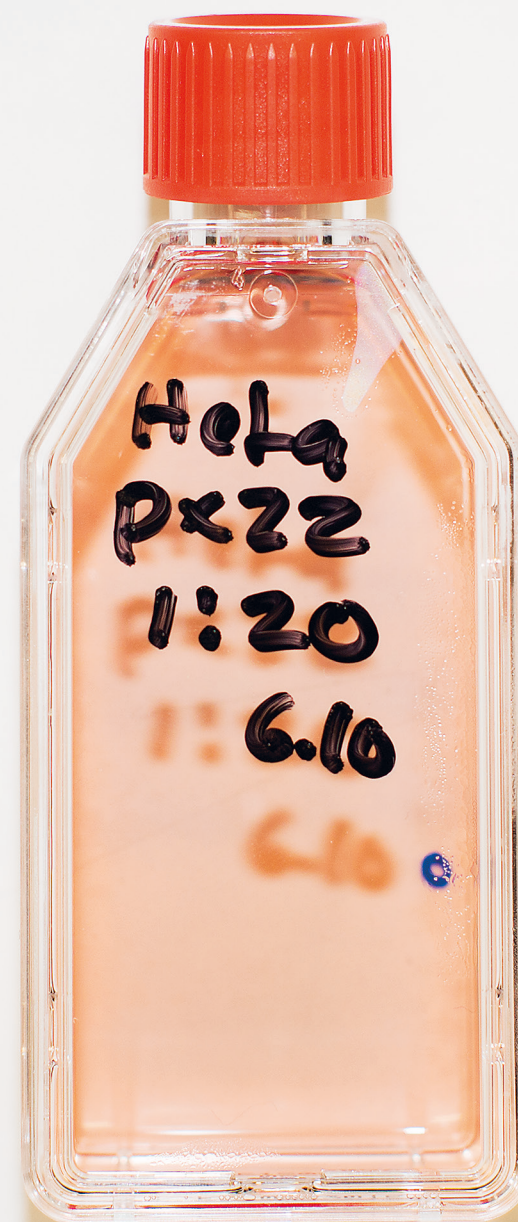
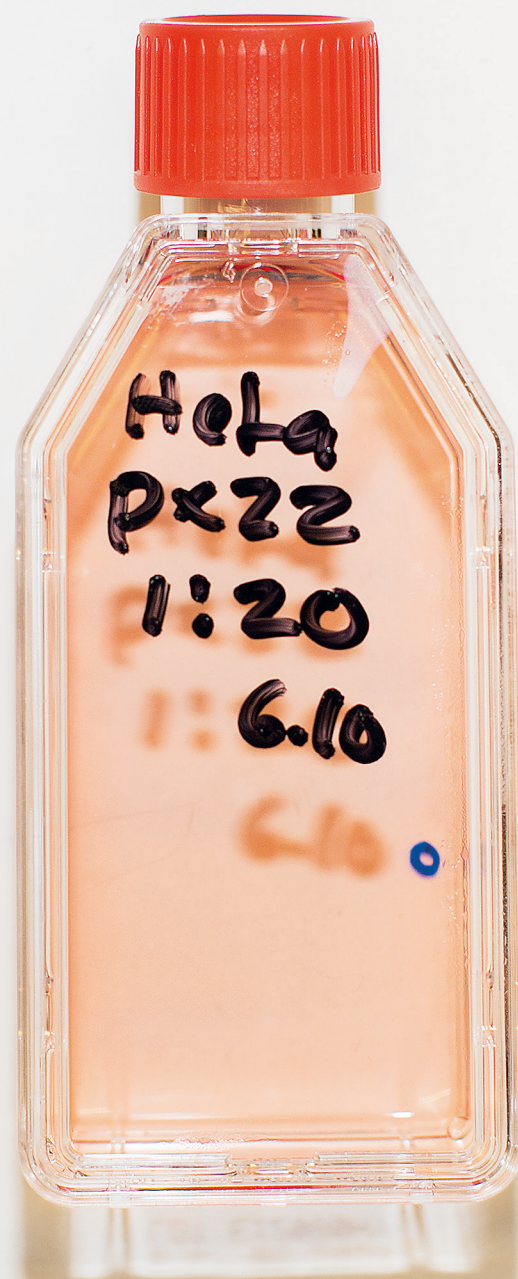


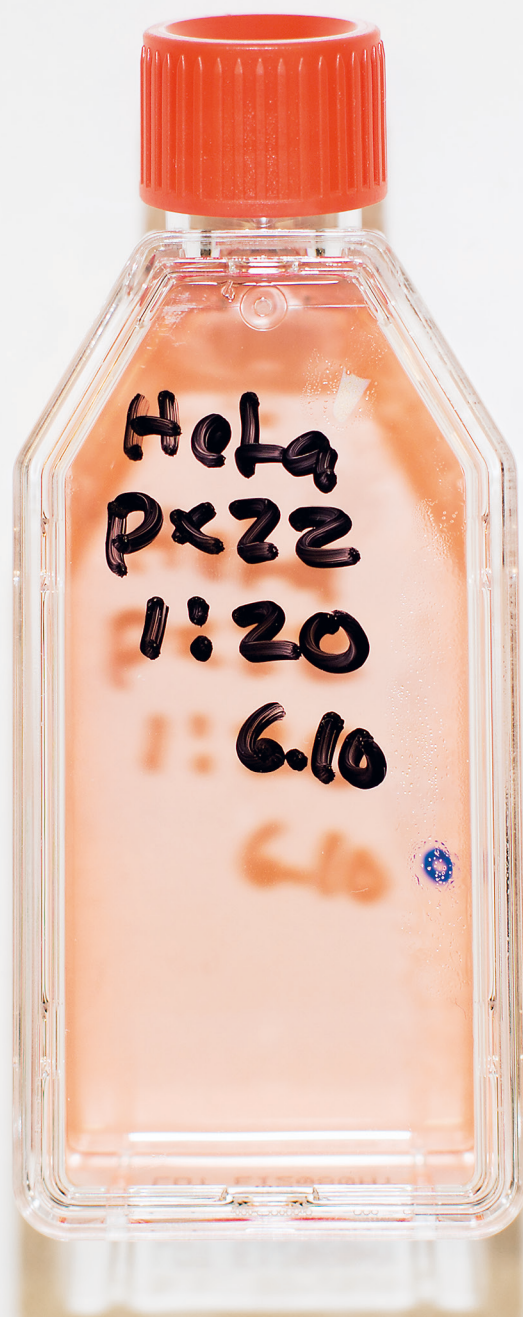


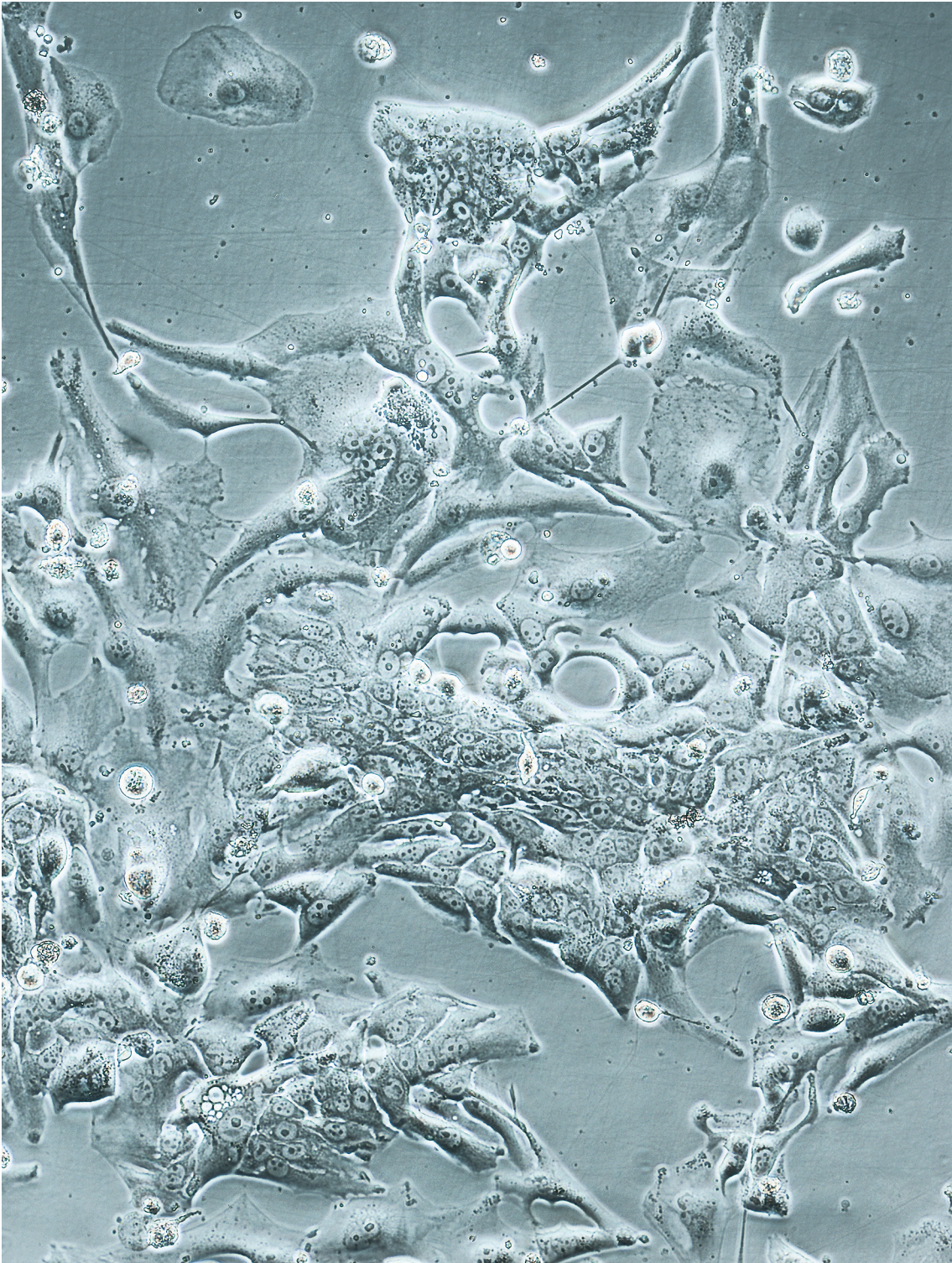


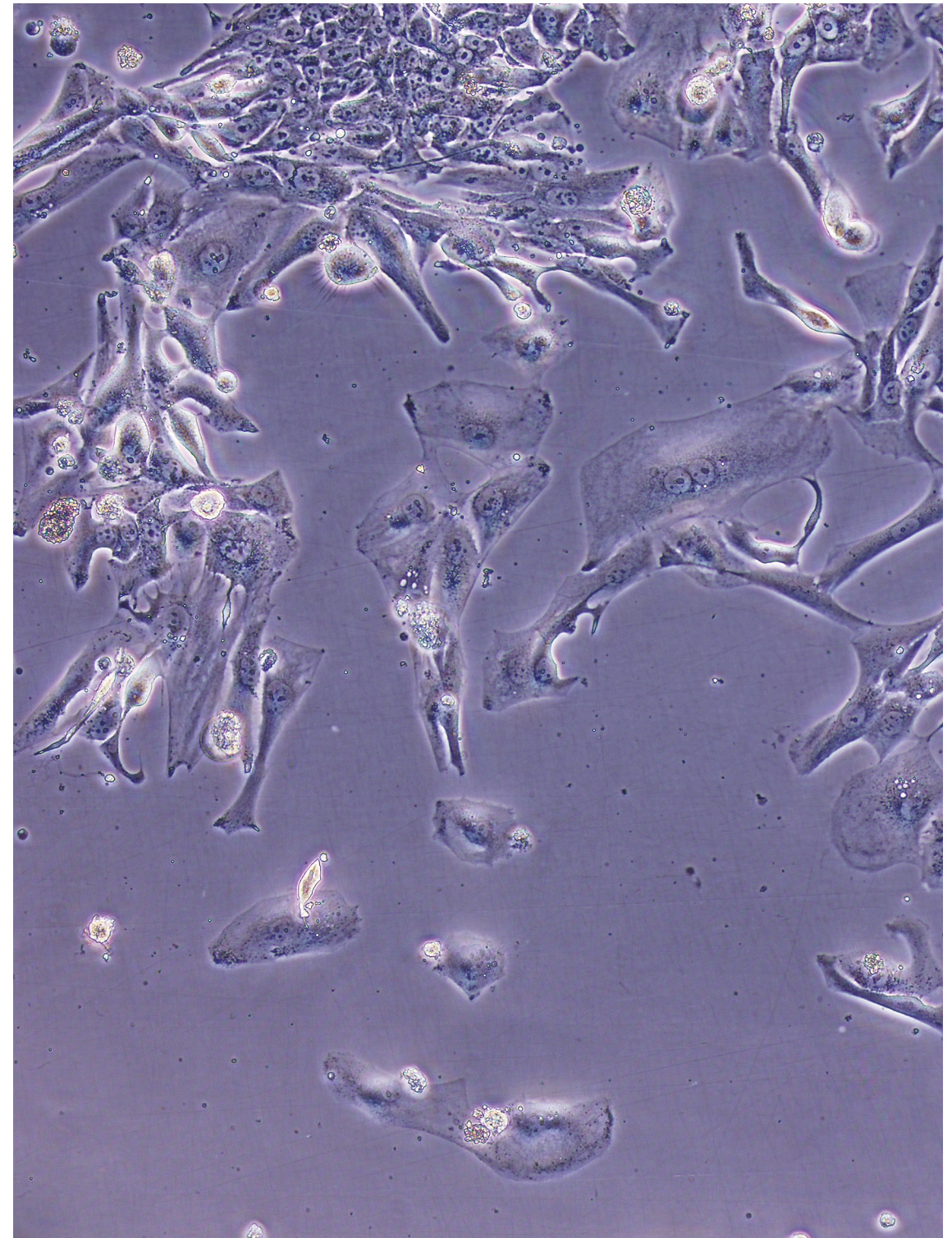
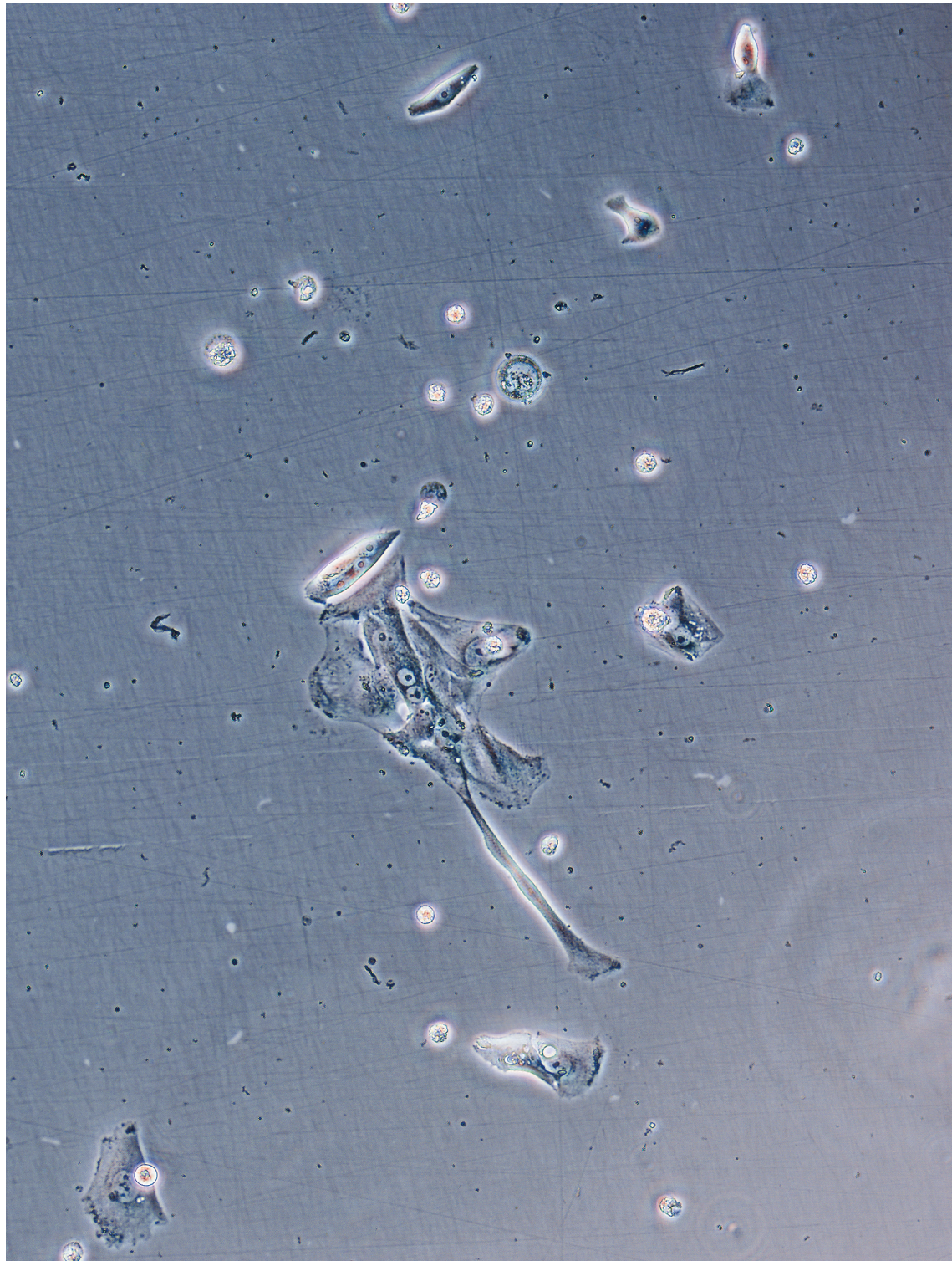


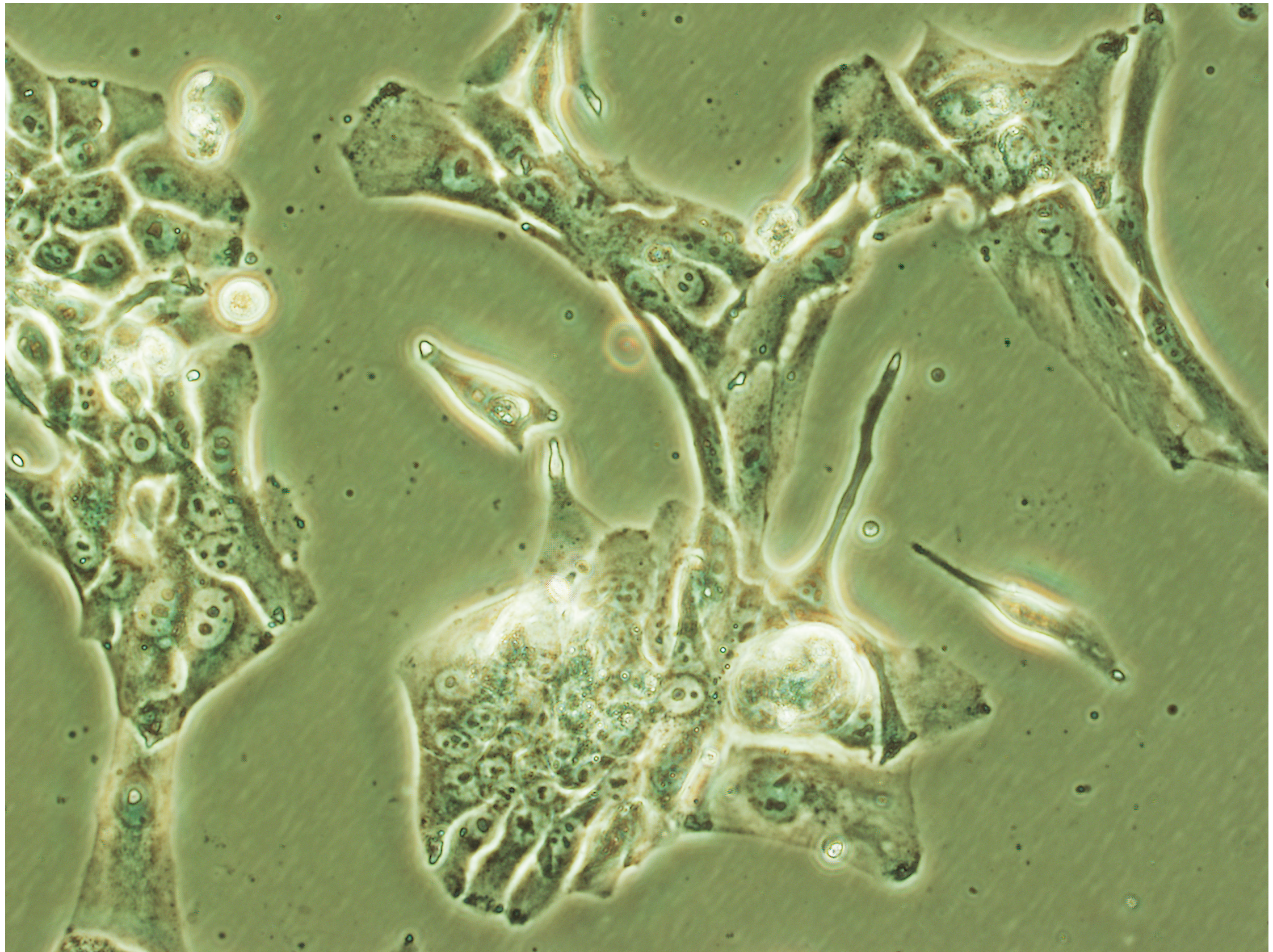


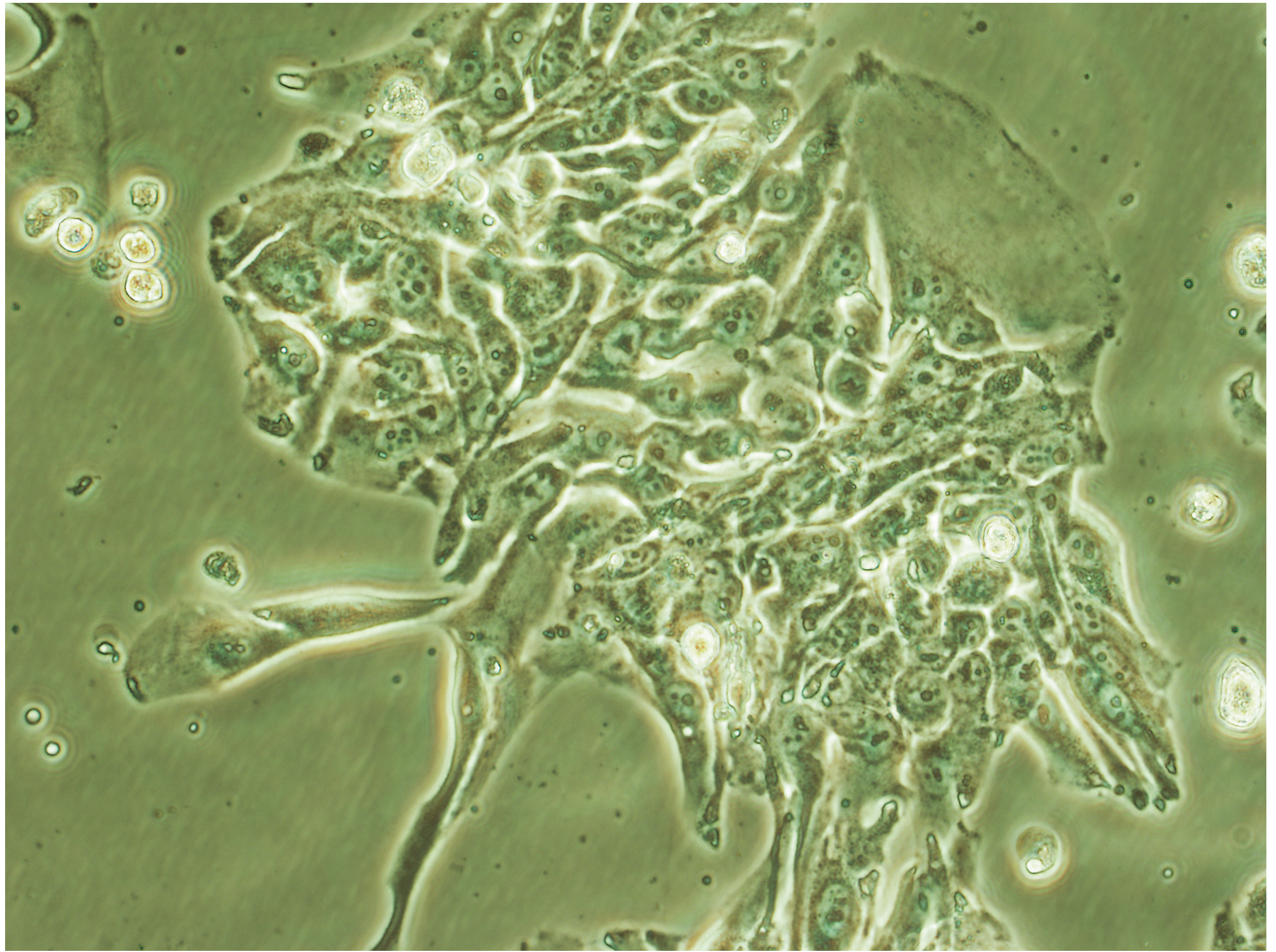


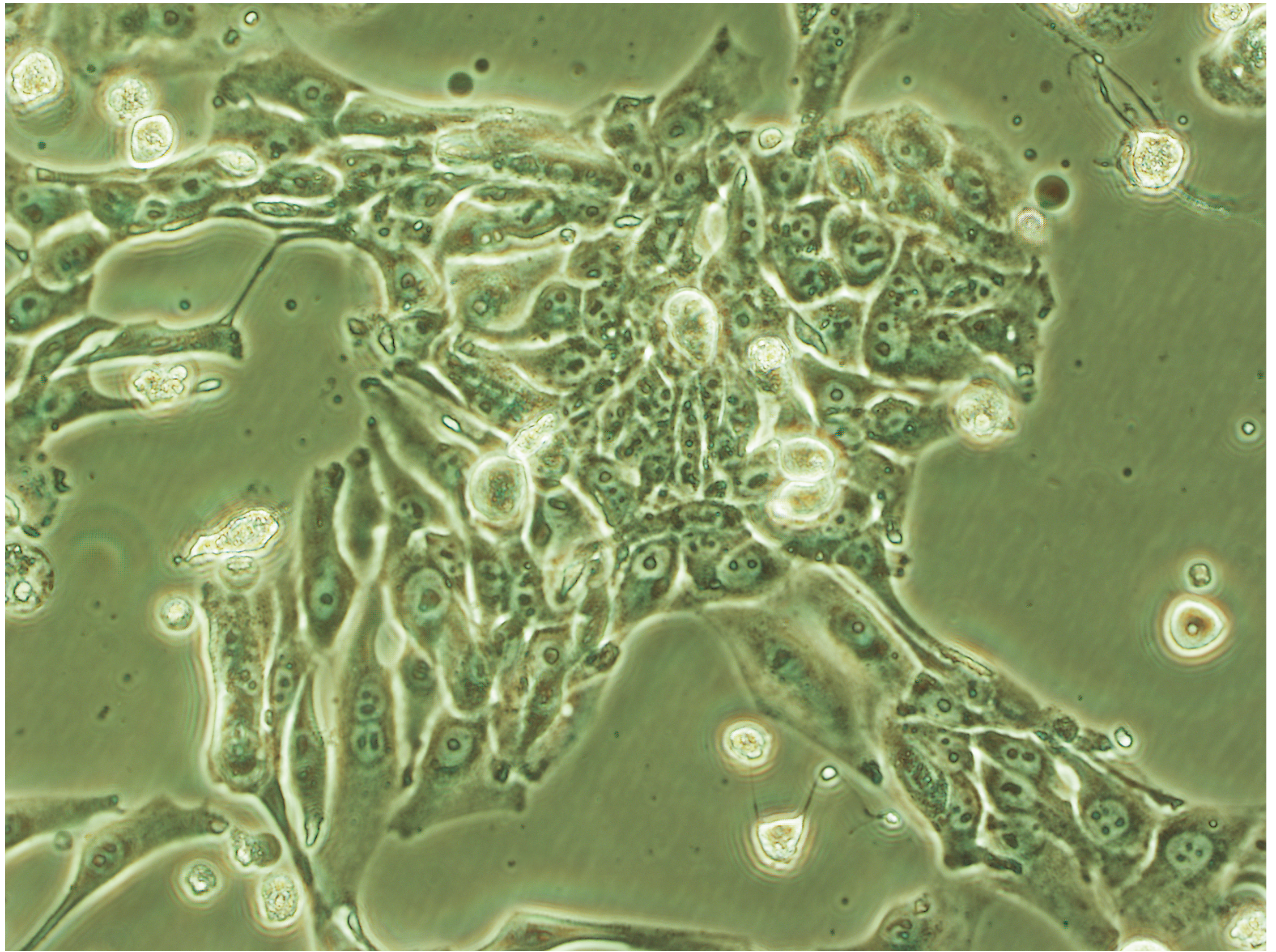


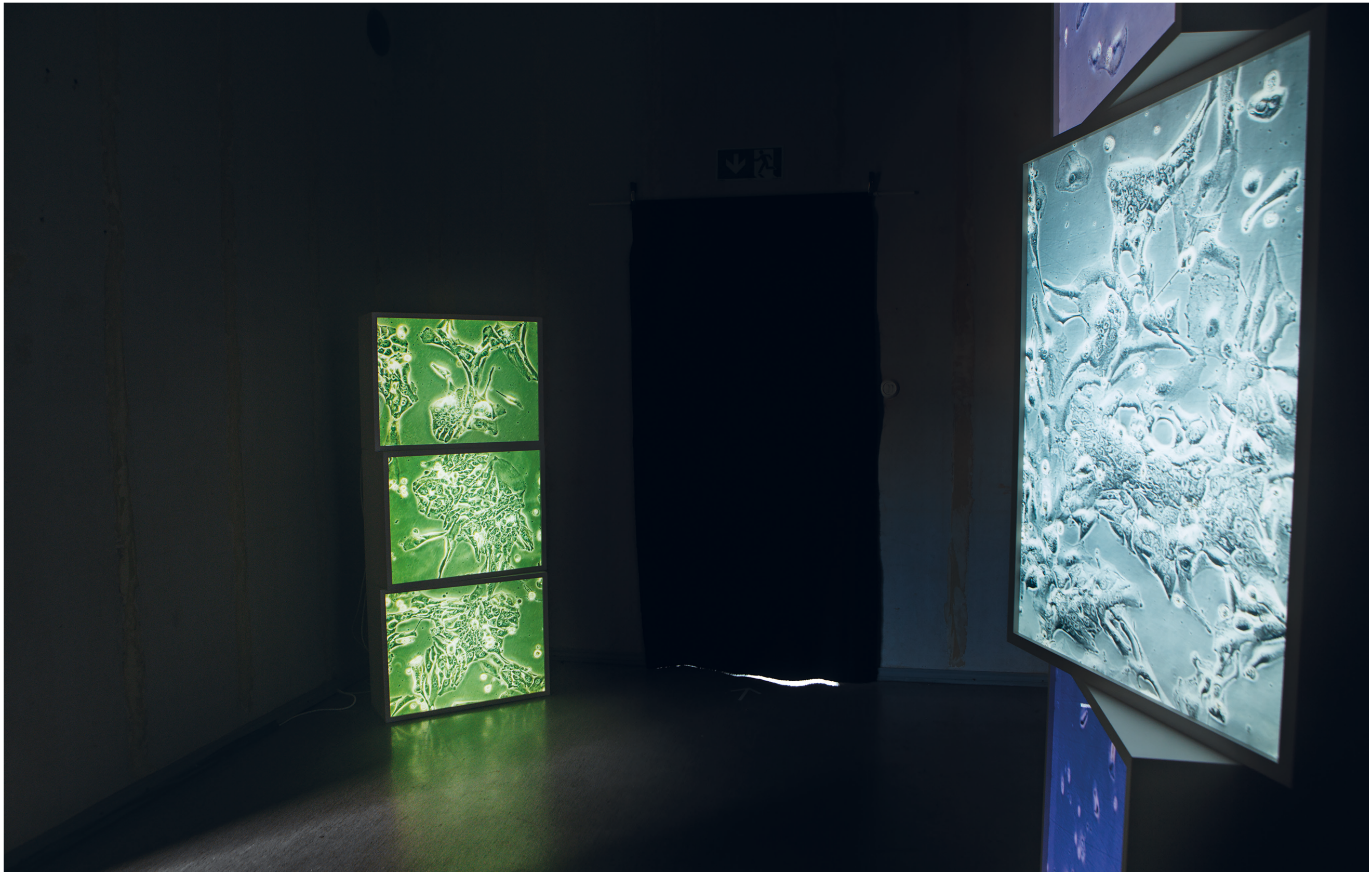




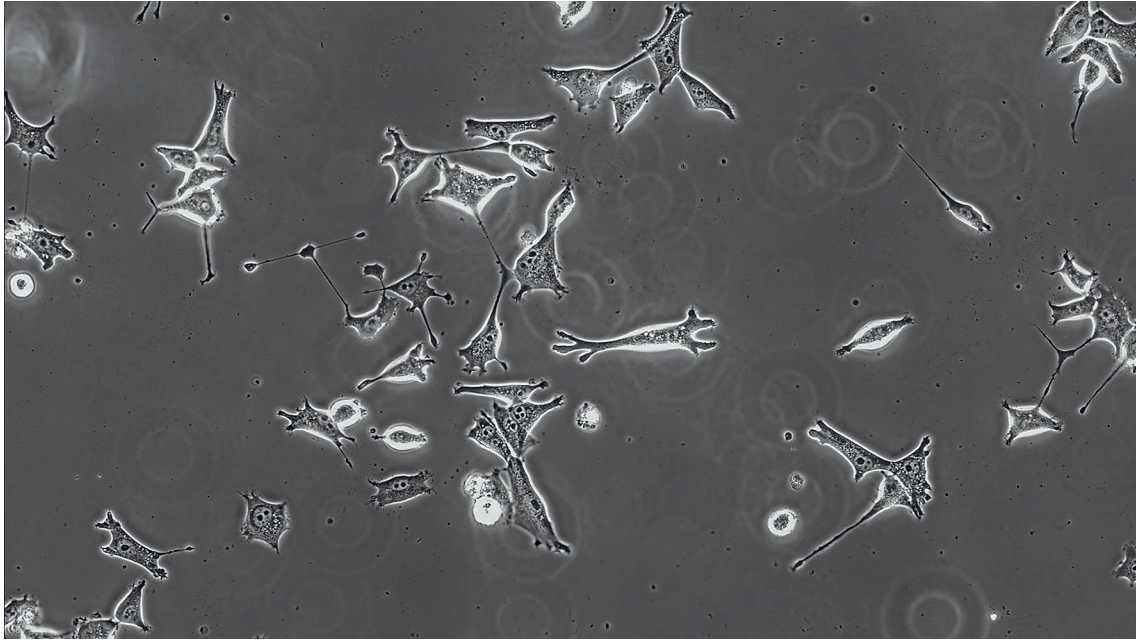






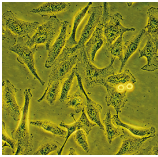








Origin, 2016.
From the series *White Rabbit Fever*.
Vinyl fabric, 373 × 314 cm.



Day 15170, MDA231, 2015.
Archival inkjet print on backlit film,
12 × 12 cm.



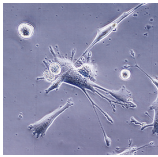
Day 18, 2015.
Archival pigment print, 120 × 80 cm.



Day 23383, HeLa, 2015.
Archival pigment print, 22 × 33 cm.



Day 1, Marcel, 2015.
Archival pigment print, 22 × 33 cm.



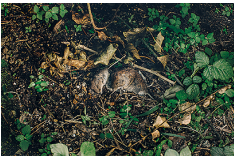
Day 11924, Pa-Ju, 2016.
Archival inkjet print on backlit film,
12 × 12 cm.



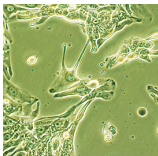
Day 79, 2015.
Archival pigment print, 120 × 80 cm.



Day 23385, HeLa, 2015.
Archival pigment print, 22 × 33 cm.



Day 1, Mice, 2016.
Archival pigment print, 22 × 33 cm.



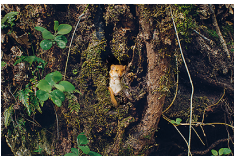
Day 2533, #3, Us-Ki, 2016.
Archival inkjet print on backlit film,
12 × 12 cm.



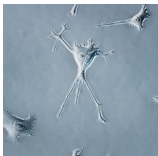
Day 100, 2015.
Archival pigment print, 120 × 80 cm.



Day 23386, HeLa, 2015.
Archival pigment print, 22 × 33 cm.



Day 1, Dormouse, 2016.
Archival pigment print, 22 × 33 cm.



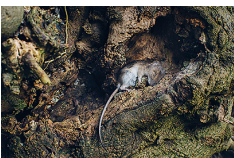
Day 11799, Pa-Ju, 2015.
Archival inkjet print on backlit film,
12 × 12 cm.



Day 23379, HeLa, 2015.
Archival pigment print, 22 × 33 cm.



Day 2538, Us-Ki, 2016.
Archival inkjet print on backlit film, light
box, 60 × 80 cm.



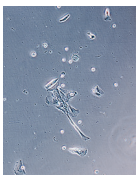
Day 1, Mouse, 2016.
Archival pigment print, 22 × 33 cm.



Day 1, 2015.
Archival pigment print, 120 × 80 cm.



Day 23380, HeLa, 2015.
Archival pigment print, 22 × 33 cm.



Day 2541, Us-Ki, 2016.
Archival inkjet print on backlit film, light
box, 60 × 80 cm.



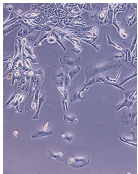
Installation box, 2016.
Oak, LED compartment, batteries,
14 × 14 × 14 cm.
Designed by Feodor Mayow.
Photograph by Roberto Luigi Apa.



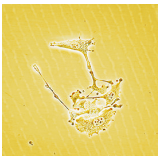
Day 11, 2015.
Archival pigment print, 120 × 80 cm.



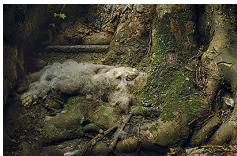
Day 23381, HeLa, 2015.
Archival pigment print, 22 × 33 cm.



Day 2538 #2, Us-Ki, 2016.
Archival inkjet print on backlit film, light
box, 60 × 80 cm.



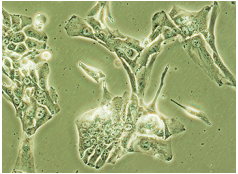
Day 11805, Pa-Ju, 2015.
Archival inkjet print on backlit film,
12 × 12 cm.



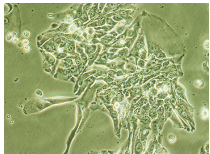
Day 17, 2015.
Archival pigment print, 120 × 80 cm.



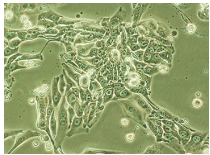
Day 23382, HeLa, 2015.
Archival pigment print, 22 × 33 cm.



Day 2533, Us-Ki, 2016.
Archival inkjet print on backlit film, light
box, 65 × 50 cm.



Day 2533 #2, Us-Ki, 2016.
From the series *White Rabbit Fever*.
Archival inkjet print on backlit film, light
box, 65 × 50 cm.



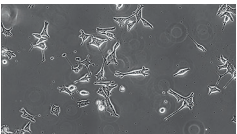
Day 2533 #4, Us-Ki, 2016.
Archival inkjet print on backlit film, light
box, 65 × 50 cm.



Light box installation at Gallery
Lapinlahti in Helsinki, Finland,
September 2016. Photograph by
Miikka Pirinen.



Archaeological, 2015.
Used radiotherapy masks, thermo-
plastic, each circa 22 × 18 x 16 cm.



Day 11799, 2016.
Three sequences of Pa-Ju cells
growing for 22 hours.
HD 1080p, 9 min., 37 sec.



Marcel Was Here, 2015.
HD 1080p, color, sound, 11 min., 33 sec.
Music by Charles Quevillon.

4.

The Artworks

In the diagram, in Chapter Three, *Leftover* (2014) is placed between disease and sickness, as the systematic portraits of used radiation therapy masks worn by a model look at illness from afar and touch on the institutional way of treating a biological body. *White Rabbit Fever* (2016) is placed nearest to sickness towards disease at the top of the diagram because the work traces sickness to its roots, to the relation to life and death, and contemplates the possibility of immortal life in the form of forever-growing cancer cells. Yet, it's towards disease because the work shows cell culture bottles and microscopic images of the cells that can be seen to represent a biomedical perspective.

This chapter presents *Leftover* and *White Rabbit Fever*. Because both of these works are also books, this chapter concentrates on the exhibitions, and more precisely on the debut exhibitions of both works.

4.1. Leftover, 2014

Leftover was first exhibited at Photographic Gallery Hippolyte in Helsinki, Finland from January 3–26, 2014. The exhibition was approved as a part of this dissertation by Professor Jan Kaila and Doctor of Arts Harri Pälviranta. The exhibition consisted of twelve framed archival pigment prints, a sculpture, and a series of photographic prints exhibited on a table. Leftover was later exhibited in three cities in Finland, Lahti, Karjaa and Turku, as well as in Oxford, UK and Kobe, Japan³²³.

The framed prints portray an anonymous model wearing used radiation therapy masks against a white background. All the portraits are lit and composed in the same way to create a category or a system. The model's eyes are closed in all of the photographs. The masks have been collected from three different university hospitals: Helsinki University Hospital, Turku University Hospital and Tampere University Hospital.

Radiation therapy masks are used to ensure that the patient is in the exact same position during each radiotherapy session. Markings on the thermoplastic masks provide a visual aid for the positioning of the patient for the treatment. The masks are made personally for each patient. After the radiation therapy treatment period, the masks are either thrown away or recycled. Over the course of a year and a half, I collected nearly 300 masks for the work.

323 The Leftover exhibition was later seen also at Gallery Uusi Kipinä, Lahti, in October 16 – September 5, 2014, at GalleriZEBRA, Karjaa, in November 7–26, 2014, at Photographic Centre Peri, Turku, in February 6 – March 1, 2015, and at Oxford University in UK in May 8 – July 7, 2015. In addition two pieces of the work were at a group exhibition at Gallery Tanto Tempo in Kobe, Japan in December 10–29, 2014.

Photographic Gallery Hippolyte's main exhibition room, where the exhibition was held, is a six-meter high, 72 square meter room. The exhibition had two framed prints in size 110 × 120 cm, and ten in size 60 × 65 cm. The sculpture, placed in the middle of the room, named *Unlimited Number of Cell Division* (180 × 180 × 195 cm) is made from over 170 radiotherapy masks melted together. The name of the sculpture refers to a medical definition of immortality and to a cancer cell's theoretical (and to a cancer cell line's practical) ability to divide eternally. This is a theme that I revisit in *White Rabbit Fever*.

The artist statement of the work is a fictitious dialogue with an imaginary cancer. The dialogue uses irony to comment on the way cancer is sometimes erroneously thought to be an entity that has its own agenda.

Are you here now? Somewhere in me, growing in secret?
My existence begins when you get to know me, you reply.
I don't want to know you then, I say.
What you want is irrelevant when it comes to me. I have no agenda.
Knowledge, treatment and hope. I have all that.
Might help, might not. Fifty-fifty. Do you want to meet and talk about it?
No! Thank you, I am busy with other things.
I have time. I just multiply.
I would rather meet you later then.
What are you so busy with?
I don't know... life.
I am part of life, brainless lump of your cells, part of you.
Are you trying to say that you are here now?
[No answer]
I cannot feel you.
Yet, you say.
Yet, I say. Give me ten more years.
[No reply]
Fine. Let's meet, I say. Where do you want to meet? Somewhere where you can smoke?
I'll be right here.
How do I recognise you?
I'll find you, don't worry about that.
That is what worries me.

The exhibition also had a table installation consisting of twelve pigment prints (size 20 × 30 cm) from my earlier work *Removals* (2011–2013). The archival pigment prints were presented on a narrow table covered with a plexiglass plate. The photographs depict the most common diseases, but only the surgically removed parts. The photos are taken a few minutes after the operations, placed in kidney bowls and lit by an operating room light. The series was made at two hospitals in Tampere, Finland.



Leftover exhibition poster.
Design by Ville Tietäväinen.



Maija Tammi: *Goitre #1*, From the series *Removals*, 2011–2013.

German publisher Kehrer Verlag published the double book *Leftover/ Removals* in Fall 2014. The book is designed by Ville Tietäväinen. Both sections of the book have 25 colour photographs, and the images of the removed gallstones, goitres and tumours are accompanied by transcribed conversations. In the conversations, three surgeons talk about the photographs while eating doughnuts; they are trying to recognise the removed part but they are also commenting on the looks of the removal and aesthetics of the image.

B: What's that?

A: I could imagine that it's an ummm...

M: Is it a goitre?

A: Yeah, a goitre because they've probably used Harmonic and you can see the polar burn marks in lines right there. I could imagine it's a goitre.

B: This is beautiful.

A: Yes it is, extremely beautiful.

B: It must have caused symptoms.

A: That one must create some pressure. I guess the indication is right, if there's like half of an apple growing out of the neck.

B: Yeah.

A: It's pretty big too.

M: It looks benign, there are no lumps, and the capsule looks intact.

A: We are quite satisfied with this, aren't we?³²⁴

Examining previous research and the ethical issues of showing suffering or sufferers in Chapter Two influenced the making of *Leftover*. I wanted to create an artwork that would go beyond the dichotomy of whether something should or should not be shown and examine different possibilities of representing sickness. I desired find a way to use personal traces of illness – patients' individual masks – without making the series about a specific illness experience, but rather, to represent a more generalised illness experience. Therefore, I chose to portray a model wearing the masks instead of photographing just the masks, as I aimed to create a reflective surface for viewers to review their feelings and attitudes about cancer instead of showing an 'other' who is sick. In addition my aim was to comment on cultural, often misguided, constructions of cancer (cancer seen as an invading monster), which the artist statement aims to reflect.

As noted in Chapter Two, people have a tendency to overestimate the consequences of being ill in general; consequently I figured this could work to my artwork's favour, as people might over-project feelings on the images. That is, I hoped that these images depicting plastic waste from a hospital treatment worn by a healthy model would communicate and invite

³²⁴ M Tammi, *Leftover/Removals* (double book). Kehrer Verlag: Heidelberg, 2014, p. 6.

reflection on the illness experience and stimulate strong feelings, even without accompanying the images with textual data or illness experience stories.

The choice to make a systematic portrait series was influenced by the historical uses of photography, as described in the research in Chapter Three. I wanted to create a category, and a feeling of a multitude of cancer cases to highlight the statistical frequency of getting or having cancer. I also researched the mechanisms of cancer, its biological aspects. Thus the sculpture *Unlimited Number of Cell Divisions* refers to cancer cells' non-senescence, to their biological immortality.

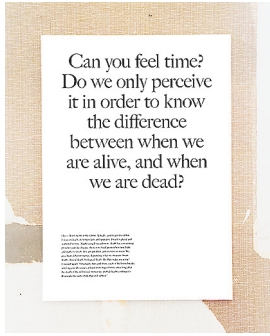
4.2. White Rabbit Fever, 2016

White Rabbit Fever continues the theme of cancer cells' potential to live forever, provided the nutrients and living space, but this time I wanted to show the actual cancer cells instead of reflecting just an idea. Therefore I examined and documented cancer cell lines, the most famous one being the HeLa cell line. While *Leftover* operates on a more symbolic level, showing only traces of sickness, *White Rabbit Fever* goes into specifics, showing the actual cells, and a decomposing rabbit, but also ventures into philosophy, to the origins of life and death.

White Rabbit Fever is presented in a separate book alongside this dissertation, published by Bromide Books in 2017. The work premiered with East Wing Gallery at the Unseen Photo Fair in Amsterdam in September 2016, and the first solo exhibition was held at Gallery Lapinlahti the same month. The work was approved as a part of this dissertation by Professor Jan Kaila and Doctor of Arts Teemu Mäki. Later, *White Rabbit Fever* was also exhibited in Turku, Rome, Tokyo and Landskrona³²⁵.

The work is a multi-part piece, consisting roughly of seven different parts: photographs / a video of a decaying rabbit, sequential photographs depicting HeLa cells growing inside a cell culture bottle, two books / a video presenting growth sequences of different cancer cell lines, microscopic images of creature-looking cancer cells in installation boxes, scenery-looking images of cancer cells in light boxes, and small skull shaped sculptures. The seventh part consists of an image titled *Origin* and four images of different animals at Day One of their decay. The presentation of the work varies with each installation and exhibition. For

³²⁵ Gallery Matéria in Rome, Italy, in January 14 – February 25, 2017, Photographic Centre Peri in Turku, Finland, in June 16 – July 9, June 2017, Kana Kawanishi gallery in Tokyo in August 5 – Sep 22, 2017, and Landskrona Foto in Sep 8–17, 2017.



Exhibition wall text at Gallery Lapinlahti, Helsinki, Finland. Sep, 29 – Oct, 16, 2016.



White Rabbit Fever at Gallery Lapinlahti, Helsinki, Finland. Sep, 29 – Oct, 16, 2016. Photograph by Miiikka Pirinen.

example either the photographic prints of a decaying rabbit are shown or a video, but not both. The combination of works is chosen according to the space. In this chapter, I focus mainly on the first exhibition at Gallery Lapinlahti.

The multitude of the works and different forms of exhibiting was partly due to Gallery Lapinlahti's exhibition space, which consists of five separate rooms. Gallery Lapinlahti is a 135 square meter gallery space on the second floor of an old psychiatric hospital building from the 1840s. The gallery has a worn out look and while some rooms are painted medium grey, other rooms have patches of worn out wallpaper. Lapinlahti was also chosen as an exhibition place due to its history as a hospital. Lapinlahti is located in central Helsinki and the building now hosts art studios, galleries, office spaces and a cafe and restaurant. In the White Rabbit Fever exhibition, the different parts of the series and the different rooms of the exhibitions were connected with texts written by American author Katherine Oktober Matthews and myself. The texts are introduced in the end of this chapter.

In addition, the separate and multiple parts of the exhibition had another purpose: to make the exhibition accessible for viewers. Because the work requires a fair amount of explaining (for example how cancer cells are immortal), I aimed to create length and room for the viewers so that there would be space for pondering and feeling the different aspects of the work. Therefore the exhibition shows, for example, cancer cell lines in different ways: the growth sequences and cell culture bottles aim to direct attention to the cell lines' growth and the clinical appearance, while the installation boxes with creature-looking cells aim to invite imagination, and the light box installation in a darkened room aim to create a physical space and experience.

Tularemia, with the common name rabbit fever, is a real disease, but White Rabbit Fever is an imaginary one, which I created as an archetype of a disease (and mortality). I was inspired by the research in Chapter Two, in which Sontag and Cotton describe the most powerful images of suffering they have encountered, and both of the images are staged or composed photographs. I planned to create a fictional disease to be able to comment on the cultural ways disease and epidemics are encountered and feared, and also as a critique against the naturalist view on disease, which has a problematic relationship with dying and death. I chose the white rabbit because of its cultural connotations as a vessel between imaginary and real. For example in Lewis Carroll's *Alice in Wonderland*, (1865) the white rabbit leads Alice into the magical world, and in the movie *The Matrix* (1999) the protagonist is told to follow a white rabbit, whereby he ultimately discovers reality. The rabbit (and hare) is also a common symbol in arts, for example in artist Joseph Beuys' performance piece *How to Explain Pictures to a Dead Hare* in 1965.

The initial planning of White Rabbit Fever took place during the Ebola epidemic in 2014 and the worldwide hysteria of it. In addition, I was also influenced by my own experience as a Red Cross Media Delegate at one of Sierra Leone's Ebola treatment centres.

The core of White Rabbit Fever orbits around two timelines: the first shows the decay and eventual disappearance of a rabbit, and the other shows the growth of immortal human cell lines that have outlived or will outlive the patients from whom they were extracted. With the work, I desired to look at time in relation to life and death. Time is essential to our being as the amount of time we think we have left to live dictates most of our actions and desires, as psychologist Laura Carstensen's theory explains.³²⁶ Next I will introduce the different parts of the work more in detail.

Part 1: The Rabbit(s)

The sequence depicts the decay of a rabbit over period of one hundred days in Grez-sur-Loing, France. The rabbit, who I named post-mortem Ralph, was placed on the stone steps leading to an abandoned cellar. I also had another rabbit, Marcel, decaying deep in a forest. I protected both rabbit corpses with rabbit nets and wooden boxes to prevent big animals from eating them. The rabbits were bought from a Parisian restaurant, and I documented them daily for three and half months.

The rabbit sequence was my way to visually examine and imagine the arbitrary nature of the different definitions of death. I desired to see and experience the decay of a rabbit, and photograph it in a way that would not cause instant aversion but invite contemplation and maybe even aesthetic pleasure, to test Carolyn Korsmeyer's theory on aesthetic disgust. Korsmeyer's theory will be introduced in the next chapter.

The exhibition series shows Ralph on Days 1, 11, 17, 18, 79 and 100. On Day 11 maggots are visible in the image, Day 17 shows the rabbit's fur becoming loose, and on Day 18 the rain flattened the loose fur. The framed photographs are 120 × 80 cm in size. Marcel became a video art piece titled *Marcel was here* (HD 1080p, colour, 12 min., 31 sec.), and the video premiered at Our Festival (Meidän Festivaali) 2016. The video was performed with Pekka Kuusisto playing violin and Anna-Mari Kähärä singing.³²⁷ Later a version of the video was combined with Charles Quevillon's song *Nirvana*, where Quevillon is counting to 666 in French.



A wooden box wrapped with rabbit net protected Marcel's corpse between the shoots, 2015.

326 L. Carstensen, 'The influence of a sense of time on human development', *Science*, Jun 30; 312(5782): 1913–1915, 2006.
327 The concert was held as part of Our Festival at Olympia-kasarmi in Tuusula, July 30, 2016.



A well plate with Us-Ki and Pa-Ju cells, 2015.



Early designs of the installation box. Design by Feodor Mayow.

Part 2: The HeLa cell culture bottle

The HeLa cell line is a cancer cell line derived from an American woman named Henrietta Lacks, who died in 1951. The cells have been grown in laboratories all over the world since then. The exhibition shows a sequence of HeLa cells growing inside a cell culture bottle for the period of ten days, the images are titled: Day 23379 – Day 23387. The day count represents the number of days the HeLa cells have been kept alive since the death of Henrietta Lacks.

The nutrient fluid in the bottles is pH sensitive and change colour as the cells divide and grow, which causes the fluid to become more acidic, turning the nutrient fluid more yellow. The framed images are 22 × 33 cm each.

I documented the growth of HeLa cells at Haartman Institute’s laboratory in Helsinki, Finland.³²⁸ With the aid of Professor Emeritus Leif Andersson, I also got to know and document other immortal human cells lines, such as the Pa-Ju cell line, derived from a Finnish teenage patient in 1983. This cell line was visually the most interesting one, and I also traced the history of the cell line to be able to understand how cell lines are born and kept alive, and why. The story of Pa-Ju cell line is presented at the end of the book *White Rabbit Fever*. The text was also published as a science article in *Suomen Kuvalehti* in the spring of 2016.³²⁹ Professor Andersson and I followed the growth of several individual cell lines twice a day.

Cancer cells are biologically immortal. Most human cells die after 40–60 cell divisions; in normal cells, telomere, a region of repetitive nucleotide, gets shorter every time the cell divides, and when the telomere is too short the cell cannot divide anymore. Cancer cells, however, have an active enzyme that rebuilds the telomere every time, which means that cancer cells can divide eternally, provided sufficient nutrients and living space.

Part 3: Cell line growth sequences (books and video)

Two books, roughly A5 in size, present the microscopic growth sequences of HeLa, Pa-Ju and Us-Ki cell lines, which I also documented at the Haartman Institute in Helsinki. At the exhibition the books were displayed on a table inviting people to leaf through them. The microscopic photographs are accompanied with the date and time when the image was taken.

328 The documentation of the cells took place between October 2015 and February 2016.
 329 Maija Tammi, ‘Kuolemattomat: 195 kuollutta suomalaista jatkaa olemassaoloaan ikuisesti – laboratorioissa’, *Suomen kuvalehti*, April 10, 2016, <https://suomenkuvalehti.fi/jutut/tiede/kuolemattomat-195-kuollutta-suomalaista-jatkaa-olemassaoloaan-ikuisesti-laboratorioissa/>

One book displays growth sequences of HeLa, Us-Ki, and Pa-Ju cell lines growing over the course of 10–14 days, and the other shows Pa-Ju cells growing during a period of 22 hours. For the Landskrona Foto Festival in September 2017 the Pa-Ju cells growing for 22 hours was reworked into a video piece, 9 minutes 37 seconds in length. In addition the different growth sequences and cell images were made into a 20-minute video piece performed with musician Pekka Kuusisto at Our Festival 2016.³³⁰

Part 4: Creature-looking cancer cells in installation boxes

Pa-Ju, Us-Ki and MDA231 are immortal human cancer cell lines similar to HeLa. Pa-Ju was derived from a Finnish teenage patient in 1983, Us-Ki in 2009 and MDA231 originates from 1970s. Images of these cells resembling creatures are displayed inside small wooden boxes with light compartments designed by Feodor Mayow and myself, and the wood parts executed by Artproof Oy.

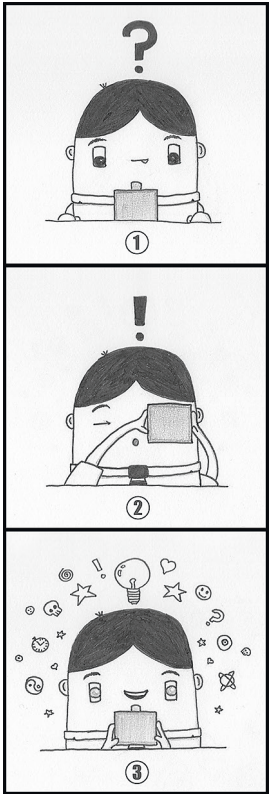
The boxes are approximately 14 × 14 × 14 cm in size. There is a battery operated LED compartment inside each box to illuminate the prints designed and built by Mayow and myself. The front wall of the box has an eye-hole to look through: the viewer has to lift up the box and peer inside to see the image. There are five boxes.

The boxes were a way to experiment with the viewing experience. I wanted to make people engage with and hold the idea of immortality in their hands, and to be possibly surprised by the creature-looking cells inside the boxes, instead of seeing the images on a wall. Despite the production of the boxes being more challenging than anticipated, it was extremely interesting to learn how to vacuum form and construct a light compartment.

Part 5: The light boxes

Six microscopic images of Us-Ki cells were displayed on box-shaped light boxes that could be stacked on top of each other. The microscopic photographs show scenery-looking clusters of cells; half of the images show cells green in colour, and the other half are bluish and violet. The boxes are 60 × 80 × 50 cm and 70 × 50 × 25 cm in size. They were installed in a darkened room in a sculptural form, reaching to the height of 2.4 meters. My aim was to create a spatial experience, and to make the cells ‘larger than life’.

330 The concert was held as part of Our Festival at Järvenpää Church, July 24, 2016.



Instruction on how to use the installation boxes. Cartoon by Tom Ivey.



Archaeological 1–10, 2015. Used radiotherapy masks, thermoplastic. Photograph by Miikka Pirinen.



White Rabbit Fever at Gallery Lapinlahti, Helsinki, Finland. Sep, 29 – Oct, 16, 2016. Photograph by Miikka Pirinen

Part 6: The Sculptures

Archaeological 1–16 are skull-shaped sculptures made of used blue radiotherapy masks. The act of shaping has distorted the masks so that instead of resembling human skulls they look alien.

Part 7: Origin

The image titled *Origin* is a large vinyl fabric print in size 373 × 314 cm. It depicts a dense forest in Mazzano-Romano, Italy. At the exhibition it covered a full wall in the first room of the exhibition. In the same room as the vinyl print, there were also four small images, 33 × 22 cm in size, presenting a dormouse, two mice, a rabbit and a mouse. The four images show Day One of their decay.

The texts

The gallery visitors were guided through the five rooms of Gallery Lapinlahti in a circular path, led by texts written by Katherine Oktober Matthews and myself. The text plates were designed by Jesper Vuori. All plates had a large text in the middle and some also a smaller text at the bottom.

‘Do you want to live forever?’, asked the text plate at the entrance. In the first room, alongside the vinyl print *Origin*: ‘Is it so, that everything with a beginning must have an ending?’ followed by a general introduction of the work. In the second room, alongside the framed rabbit prints: ‘Can you feel time? Do we only perceive it in order to know the difference between when we are alive, and when we are dead?’ followed by:

‘Day 1. Don’t mention the rabbit. Actually, just forget the rabbit. Focus on death, its temporality and spatiality. Death is plural and scattered in time. Rephrasing Foucault now: death has a swarming presence just like disease, there is no fixed point when time halts and starts to revert. It is already there and in every moment. We give them different names, depending what we measure: brain death, clinical death, biological death. Do they make any sense? Foucault again: “Gradually, here and there, each of the knots breaks, until organic life ceases, at least in its major forms, since long after the death of the individual, minuscule, partial deaths continue to dissociate the islets of life that still subsist.”

In the third room with a sequence of HeLa cell line culture bottles: ‘How would time feel, without death? Another endless direction to gaze towards, like staring up the stars?’ with a text:

‘Day 23379. Immortal human cells, cancer cells growing in a laboratory. The HeLa line: derived from a woman named Henrietta Lacks in 1950s. Pa-Ju line: derived from a Finnish teenage patient in 1983. And Us-Ki, from a Finnish patient in 2009. All continuously grown in laboratories, cell division after cell division, decade after decade. Eternally exceeding the life expectancy.

They say that the amount of time we think we have left to live dictates most of our actions and desires. Disease assaults the conception of time. Foucault again, referring to Bichat: “It is not because he falls ill that man dies; fundamentally, it is because he may die that man may fall ill.”

At the entrance to the fourth, darkened room with the light box installation: ‘The end pulls you like gravity, is it so? Don’t be frightened, into the dark you go.’ In the fifth and final room, which was separated from the main rooms by a corridor, the sculptures were presented accompanied by the text:

‘Long after we’re gone, when our bones have turned to dust, animals searching for food or intelligence will uncover plastic bags imprinted with “Buy Now, Pay Later!” and wonder what it means.’

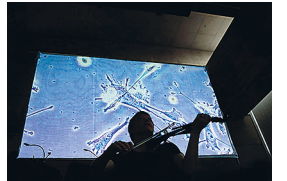
The book

The book *White Rabbit Fever* was published by Bromide Books in Summer 2017. The book is bilingual; English and Japanese. It contains 108 colour photographs and texts by Katherine Oktober Matthews. The book is divided into four chapters, and ends with an article titled *Immortals* that traces the history of the Pa-Ju cell line. The book is designed by Jesper Vuori.

4.3. Reflection

The artworks *Leftover* and *White Rabbit Fever* set out to examine new ways to think about and create photographic art about sickness. As Kleinman’s definitions of sickness, illness and disease gave a backbone to the research from the start, I aimed to make artworks of sickness or disease, and avoid the illness experience as it is the most commonly used perspective, as shown in the previous chapter. *White Rabbit Fever* was also a visual way to challenge the core definitions of the overall research by looking at the arbitrariness of the definition of sickness.

While in *Leftover*, I used discarded radiation therapy masks in an art context, in *White Rabbit Fever* I connected scientific methods and practices



Day 11799, HD 1080p, colour, 20 min., (2015). Performed with Pekka Kuusisto at Our Festival, 2015. Photograph by Maarit Kytöharju.

into the making of the artwork. I operated with very tactile, biological definitions of death and immortality in the work to invite philosophical contemplation, which I possibly achieved; artist–researcher Teemu Mäki, one of the academic reviewers of the exhibition, writes in his report, that the artwork summons and challenges the viewer to reflect on one’s relationship to death, and on the human position as a ‘discontinuous being’.

With *Leftover* I hoped that people will project their own feelings on the images. With *White Rabbit Fever* I aimed at making decay and disease approachable without losing the visceral. What I did not anticipate was that the creature-looking cancer cells in the miniboxes might disturb people. These images, at a conference presentation at Helsinki Photomedia 2016, produced visceral responses in some viewers when combined with the information that they are cancer cells.³³¹ The next chapter attempts to understand why some photographs disturb and fascinate at the same time.

³³¹ Two participants described their visceral disgust reaction during the discussion section of the presentation; Maija Tammi, ‘Uncanny and the proximity of photographs’, Helsinki Photomedia Conference, April 1, 2016, Aalto University, Helsinki, Finland.



The Difficulty of Looking



Maija Tammi: *Breast cancer (whole breast removed) #1*. From the series *Removals* 2011–2013.



Maija Tammi: *Gallstone #1*. From the series *Removals* 2011–2013.

‘That is lasagna and that is a peanut’, a middle-aged man wearing a light brown coat comments aloud at the TR1 art gallery in Tampere, Finland. He seems delighted at his recognition. The man is looking at two of my photographs from the series *Removals*. The series consists of gallstones, cancers and other chronic disease-related removals shot at two hospitals in Finland just a few minutes after the operations. The ‘lasagna’ is actually a breast removed because of cancer and the ‘peanut’ is a gallstone in a kidney bowl. The man is just about to turn to leave when he glances back once more, as if he had forgotten something. He bends slightly to read the titles of the photographs – and winces in apparent disgust. He straightens his back and looks as though his best friend has just stabbed him. The man at the gallery seems to be in a state of unease; he seems to be as disturbed as when confronted with a real wound with blood and pus.

Why is it sometimes difficult to look at photographs of sickness? In this chapter I am trying to find tentative answers to this question by studying the concept of abject in relation to representations of sickness. Abject was first articulated by Georges Bataille and developed further into its most known form by Julia Kristeva in 1982 in her book *Powers of horror: An Essay on Abjection*. In addition to their work, I draw from psychological, philosophical and sociological research; and from Carolyn Korsmeyer’s writing on aesthetic disgust. I will first outline the history and the concept of abject, then examine abject in relation to disgust, uncanny and art, and then apply the concept to photography. As examples, I am addressing Max Aguilera-Hellweg’s photographs of invasive surgeries and my own photographic series of disease-related removals.

I am using Kristeva’s definition of abject in this chapter because its starting point is in surplus, in something that has been pushed aside from the normal and healthy, and because it aims to understand instead of just stating an experience or explaining a behaviour. Also, as it is a concept that combines psychoanalysis, anthropology and literature research, it is not tied to just one specific research field but connects parts of each.

5.1. Abject and its brief history

In brief, abject can be described as something excess, secreted or jettisoned that questions the boundaries of the bodily self and identity. It is entwined between disgust and fascination, and in between subject and object, a sort of a state of nonbeing. It is a slimy term that threatens itself.³³²

332 J Kristeva, *Powers of horror: An essay on abjection*, Columbia University Press, New York, 1982.

The French surrealist Georges Bataille articulated the term abject already in the 1930s although it was not really conceptualised until the 1980s. Bataille, who was also a sociologist and a philosopher, wrote a short essay in 1934 entitled *Abjection and Miserable Forms*. The essay commented on the polarisation of class struggle in France at that time and was published in *Essays on Sociology*. In his essay, Bataille writes that the misérables, by which he means the oppressed and poor in society, have become abject themselves because they have no way of avoiding contact with real abject things such as filth and rats.³³³ For Bataille, abject becomes a synonym for the misérables. He defines abject things ‘as objects of the imperative act of exclusion’³³⁴ and assimilates this act of exclusion to the psychoanalytic explanation of anal eroticism. For all its deliberations on the abject, Bataille’s short essay of just a few pages leaves a lot to interpretation.

American art critic Rosalind Krauss interprets Bataille’s abject as a fluid concept that also goes beyond the physical objects of disgust. Krauss writes that Bataille was ‘interested in splitting apart of meaning from within since we know all acts of fission produce waste, the sun’s very brightness for example, piling up an unassimilable, excremental slag.’³³⁵ In other words, something becomes abject as a side effect of defining something as pure, sacred, lawful; defining something high will inevitably produce low, and lower than low. Krauss writes that for Bataille this excrement from the meaning-making system cannot be infused into anything else, not even with the means of politics or philosophy. However, this conceptual excrement is a force that can tear down the whole structure of the initial definition that produced it; as for Bataille, ‘the most forceful centripetal pull of society is a power not of attraction but one of repulsion.’³³⁶ Almost fifty years after Bataille’s essay, Julia Kristeva developed the concept of abject to its most known form.³³⁷

The philosopher, psychoanalyst and sociologist Julia Kristeva examines the power to disgust in her book *Powers of Horror: An Essay on Abjection*. Kristeva draws her concept of abject from psychoanalysis, anthropology, religion and literature, whereas Bataille’s starting point for abject was politics. For both, however, abject is a force that can shatter the borders of the whole system that produced it. Kristeva defines abject as something excess, secreted and contagious, something that threatens our existing body image and identity by revealing the frailty of their boundaries.³³⁸

333 G Bataille. ‘Abjection and miserable forms’ in *More & less*, S Lotringer and C Kraus (eds.) MIT Press, Cambridge, 1999, p. 8–13.
334 G Bataille, *More & less*, 1999, p. 11.
335 R Krauss, ‘Informe without conclusion’ in *October* 78, p. 89–105, 1996, p. 99.
336 R Krauss, *October* 78, 1996, p. 91.
337 S Lotringer ‘Les Misérables’ in *More & Less*, S Lotringer and C Kraus (eds.), MIT Press, Cambridge, 1999, p. 2–7.
338 J Kristeva, *Powers of horror*, 1982.

For Kristeva abject is neither subject nor object, but it is still ‘opposed to I’.³³⁹ Abject can be seen as a (non)being as interpreted by Hal Foster, who places this nonbeing at the state before a child realises that he or she is a separated being from the mother and after she or he is a corpse, the final object.³⁴⁰ Kristeva writes in her later book *Severed Head* about the abject state using Medusa, the female monster in Greek mythology who had snakes in place of hair: ‘Medusa is abject as primitive matrix of that archaic nondifferentiation in which there is neither subject nor object, only the sticky, slimy ab-ject’.³⁴¹

A major influence for Kristeva’s book was anthropologist Mary Douglas’ book *Purity and Danger*, an analysis of concepts of pollution and dirt, published originally in 1966. Douglas’ book is an anthropological examination not just into primitive tribes, but also into developed societies in order to show that human behaviour is universal when it comes to dirt. According to Douglas dirt is produced by the human condition to yearn for clear concepts, borders and classifications:

‘Where there is dirt there is a system. Dirt is the by-product of a systematic ordering and classification of matter, in so far as ordering involves rejecting inappropriate elements’.³⁴²

For Douglas, dirt, something that is out of its place, is dangerous but also powerful. Dangerous because it does not fit, it disturbs, so must be pushed away and avoided. Powerful, because dirt has ‘a half-identity’: it can still be recognised where it originated, and its mere presence threatens the pure, but at the same time dirt is formless. This formlessness in turn is an invitation for creativity and new beginnings because that is where the act of classification initially starts, from the desire to bring order where there is none.³⁴³

Kristeva defines abject to be outside the symbolic order – it is thrown out of the cultural world, only to return to confront us. By symbolic order Kristeva does not merely mean culturally shared and established classification systems, but she also takes into account the idea that different subjective structures are possible within this system. She notes that the symbolic order is rooted in a universally shared signifying process, language, and abjection borders the ‘identity of the speaking being’.³⁴⁴ Kristeva argues that confronting bodily fluids and defilement place her at the borders of her ‘condition as a living being’.³⁴⁵

339 J Kristeva, *Powers of horror*, 1982, p. 1.

340 H Foster, *The return of the real*, 1996, p. 149.

341 Kristeva, *The severed head*, 2014, p. 31.

342 M Douglas, *Purity and danger*, Routledge: London and New York, (Orig. 1966) 2002, p. 44.

343 M Douglas, *Purity and danger*, 2002, p. 198.

344 J Kristeva, *Powers of horror*, 1982, p 65–67.

345 Kristeva, *Powers of horror*, 1982, p. 3.

Hal Foster, who in his book *The Return of the Real* traces avant-garde art and theory, draws a clear distinction between Kristeva’s abject and abjection, terms that he sees Kristeva treating very ambiguously. He writes: ‘to abject is to expel, so separate; to be abject, on the other hand, is to be repulsive, stuck, subject enough only to feel this subjecthood at risk’.³⁴⁶ Foster sees that the operation to abject is regulatory formation in the society whereas the condition to be abject is corrosive. Foster’s outlining of the abject is close to the Bataille construct asserting that the act of defining something high will inevitably also produce the lower than low, which has the ability to shatter the whole construct.

The psychoanalytic side of Kristeva’s book on abject draws from Freud and especially Jacques Lacan’s writings. For Lacan, coming too close to the Real induces a trauma. The Real is one of Lacan’s three registers: symbolic, imaginary and Real. In brief, the symbolic register is like a conscious language and a system of signs, the imaginary register refers to the principal illusion of being whole and autonomous, and the Real is a place beyond the symbolic and imaginary. The Real ‘can be understood as the site of incompleteness against the symbolic order’.³⁴⁷ Slavoj Žižek uses an analogy of a chess game to describe the three registers: the rules of the game are the symbolic register, the appearance of the pieces symbolise the imaginary, and Real is all the circumstances that affect the game, the players’ skills for example.³⁴⁸

Lacan calls this missed encounter with the Real *tuché*. Although Kristeva does not use Lacanian registers, her conceptualisation of abject resembles the Lacanian ‘encounter with the Real’. For example, Hal Foster positions Kristeva’s abject in relation to Lacan’s image-screen, gaze and subject of representation. He sees that abject art is ‘an attempt to evoke the real as such’.³⁴⁹ For Foster, abject art wants to be a wound or expose the wound at ‘the broken boundaries of the violated body’.³⁵⁰ He also speculates that confusion as to where or what the wound is, is the traumatic part.³⁵¹

Another aspect Kristeva borrows from Lacan’s writings is *jouissance*. According to Slavoj Žižek this ‘enjoyment’ is preserved in its original French in English texts because ‘we are not dealing with simple pleasures, but with a violent intrusion that brings more pain than pleasure’.³⁵² Another way *jouissance* can be described is ‘unconscious energy’ combining

346 H Foster, *The return of the real*, 1996, p. 156.

347 K Tavin, M Kallio-Tavin, ‘Violence and other in contemporary art: A question of ethics for art education’ in *Synnyt/Origins* (2), 60–76, 2014, p. 64.

348 S Žižek, *How to read Lacan*, W.W. Norton & Company: New York and London, 2006, p. 8–9.

349 H Foster, *The return of the real*, 1996, p. 152.

350 Foster, 1996, p. 152.

351 Foster, 1996, p. 134.

352 S Žižek, *How to read Lacan*, 2006, p. 79.

‘displeasure with a pleasurable quality’.³⁵³ Lacan’s jouissance is paradoxical in the sense that it is only enjoyable as long as it is not fulfilled. Kristeva writes that ‘jouissance alone causes the abject to exist as such’.³⁵⁴

Kristeva and Lacan share a similar take on language in general. For both Lacan and Kristeva, to understand or to comprehend something is to define it and ‘this very process has already transformed the thing’.³⁵⁵ Kristeva herself defines the abject as a ‘jettisoned object’, that ‘draws me towards a place where meaning collapses’.³⁵⁶

The main reason why Kristeva’s concept of abject became widely known and applied instead of Bataille’s definition was that Kristeva’s book was translated and therefore more widely available, unlike Bataille’s essay.³⁵⁷ German philosopher and critical theorist Winfried Menninghaus sees that Julia Kristeva’s abject is just another definition of disgust that happened to be published at a fruitful time. Rosalind Krauss on the other hand compares Kristeva’s abject to Sartre’s slimy, a state of matter in between liquid and solid: ‘But the slimy, in the form of the gagging suction of a leech-like past that will not release its grip seems to contain its own form of possessiveness’.³⁵⁸

‘It is a state of alarm and emergency, an acute crisis of self-preservation in the face of an unassimilable otherness, a convulsive struggle, in which what is in question, is quite literally, whether “to be or not to be”’, Menninghaus writes.³⁵⁹

However, Menninghaus is talking about disgust not about abject. He has traced the theoretical approach to disgust, during a period of more than 250 years, from Mendelssohn, Kant, Nietzsche, Kafka, Freud, Bataille to Kristeva. In practice, disgust as an emotion and abject overlap in their meanings. However, instead of being parallels, disgust can be seen as one side – albeit a very essential side – of abject.

5.2. Abject and disgust

Literally, ‘dis-gust’ means ‘bad taste’.³⁶⁰ However, despite how natural disgust might feel, it is not just an automatic reaction. It has been shown, for example, that repulsion towards faeces is absent in early childhood.³⁶¹ We learn to be disgusted by things as well as not to be disgusted by them. A surgeon is not repulsed in front of an open surgery wound and an Icelandic person is probably not disgusted when smelling a piece of rotten shark; in most cultures adults eat some delicacies that are basically rotten.³⁶² As social psychologist Haidt et al. put it: ‘Disgust may have its roots in evolution but it is also clearly a cultural product’.³⁶³

Disgust is understood and researched as an emotion. Over the last thirty years, disgust has drawn the attention of philosophers (Korsmeyer, 2011), psychologists (Rozin, 1986, Tybur, 2013 and Pizarro, 2009) and social psychologists (Haidt et al., 1997).

It is not only filthy objects that can be abject or disgust us. Researchers often differentiate between material disgust and moral disgust. Material disgust refers to the response to possible disease-causing objects nearby and moral disgust refers to the breaking of social norms and rules.³⁶⁴

In recent psychological research, a third category has been introduced. Tybur et al. differentiate between three types of disgust: pathogen disgust, moral disgust and sexual disgust. They write that in addition to making us avoid ‘contact with the disease-causing organisms [...] disgust evolved to regulate decisions in the domains of mate choice and morality’.³⁶⁵ It is not just rotten food or bodily fluids that make us wince, but also unfairness, lying and breaking of common rules. One aspect that causes moral disgust is the violation of the concept of purity, for example: ‘a brother and sister having sex, and an avant-garde performance art piece in which performers act like nonhuman animals and urinate on stage’.³⁶⁶ These violations of rules manifest themselves on the bodies of the spectators as various physical responses. People might for example wince.

353 Y Stavrakakis, *Psychoanalysis, theory, politics*, University Press, Edinburgh 2007, p. 181.

354 Kristeva, *Powers of horror*, 1982, p. 9.

355 B Schmitz, ‘Homelessness or symbolic castration? Subjectivity, language acquisition and sociality in Julia Kristeva and Jacques Lacan’, *Hypatia*, Vol 20(2), p. 69–87, 2005, p. 70.

356 Kristeva, *Powers of horror*, 1982, p. 2.

357 Krauss, *October* 78, 1996, p. 92.

358 Krauss, *October* 78, 1996, p. 92.

359 W Menninghaus, *Disgust. Theory and history of a strong sensation*, State University of New York Press: Albany. 2003, p. 1.

360 P Rozin and A E Fallon. ‘A perspective on disgust’ in *Psychological review*, 94(1), p 23-44, 1987, p. 23.

361 J M Tybur, D Lieberman, R Kurzban, P DeScioli, ‘Disgust: Evolved function and structure’. *Psychological review*, Vol 120(1), Jan 2013, p. 65–84, p. 77.

362 Rozin and Fallon, *Psychological review*, 2013, p. 38.

363 J Haidt, P Rozin, C McCauley, S Imada, ‘Body, psyche and culture: the relationship between disgust and morality’ in *Psychology and developing societies* 9, 1 Sage Publications, 107–131, 1997, p. 111.

364 Korsmeyer, *Savoring disgust*, p. 4.

365 Tybur et al., *Psychological review*, 2013, p. 65.

366 Tybur et al., *Psychological review*, 2013, p. 74.

Wincing when disgusted has a scientific explanation. The prototypical facial expression of disgust decreases the exposed area to possible pathogens: squinting the eyes, closing the mouth, limiting airflow through the nose.³⁶⁷ However, these same facial expressions have been detected in situations where something has been only morally disgusting, and not potentially disease-causing, for example seeing an unfair game.³⁶⁸ To address why this happens, the researchers offer the explanation that this is a way to signal to others one's condemnation of the rule-breaking.

This moral or socio-moral disgust is linked by Haidt et al. to the need to distinguish ourselves as humans from animals (which reminds us of our own mortality). As an example, they note that of all the human body products, such as faeces, breast milk and semen, only one is not considered disgusting: tears, which are unique to humans.³⁶⁹ Moreover each culture has their own rules of how to properly be a human. Haidt et al. note that people also find disgusting 'frequent references to racism, brutality, hypocrisy, political attitudes, and violations of important social relationships.'³⁷⁰

The psychologist and disgust researcher David Pizarro has found a link between disgust and political affiliations. The data in two studies showed that conservatives are more easily disgusted than liberals.³⁷¹ The studies were able to show correlation but no causal effect. In another study it is tentatively proposed that disgust is a primary factor that causes people to avoid colorectal cancer screenings, which ultimately leads to more cancer deaths.³⁷²

'Of course disgust may be misdirected. It requires reflection and assessment, as do judgments of reason. Just as impressions of the senses may mislead, so emotions are not free from error. Yet this does not obviate the importance of disgust as a gauge and measure of qualities and values in the world.'³⁷³

The quote is by Korsmeyer and Smith, written in the introduction of Aurel Kolnai's *On Disgust*. Philosopher and psychoanalyst Aurel Kolnai wrote *On Disgust* in 1929. For him, one of the most important features of disgust

is proximity. This proximity threatens to immerse people by its sheer closeness in the moment. By this he means spatial and physical proximity, but also sensual and functional proximity.³⁷⁴ This proximity for him also explains why something otherwise not perceived to be disgusting might become so by being too close or too much; for Kolnai disgust is also a feeling that prevents us from 'drowning in pleasure'; an excess of sweet things or sweet words can turn into disgust.³⁷⁵ Kolnai describes disgusting objects as taunting:

'Everything that is disgusting has in it something which is at one and the same time both striking and veiled, as is, say, a poisonous red berry or a garishly made-up face.'³⁷⁶

Korsmeyer and Smith interpret Kolnai's proximity to mean that disgusting things can potentially contaminate, infect or otherwise threaten the perceived cleanliness of the body.³⁷⁷ However, if disgust evolved to make people avoid things, there must be a counterbalance, a curiosity to push the borders, or humans would have never tried anything new, as David Pizarro argues.³⁷⁸ Similarly Haidt et al. place 'disgust and sensation seeking as opposing motivations'.³⁷⁹ Haidt et al. support their claim by illustrating the omnivore's strategy of fearful interest in new potential foods, and by the fact that research on sensation-seeking sensitivity negatively correlates with research on disgust sensitivity.

Could this sensation-seeking, i.e. curiosity, be defined as fascination? When disgust tells us to stay away, but we are at the same time curious, fascinated, are we not looking for possibilities to increase our understanding, or to test boundaries?

Psychological research, although concentrated on the evolved functions of disgust, validates the discussion of the abject in a larger context and offers explanations not only for the reaction but for its functions as well. In the next section, I will examine abject in relation to uncanny as the comparison helps to define what abject is.

367 Tybur et al., *Psychological review*, 2013, p. 70.
368 Tybur et al., *Psychological review*, 2013, p. 65–76.
369 Haidt et al., *Psychology and developing societies* 9, 1997, p. 113.
370 Haidt et al., *Psychology and developing societies*, 1997, p. 116.
371 Y Inbar, D A Pizarro, & P Bloom, 'Conservatives are more easily disgusted than liberals', *Cognition and emotion*, 23, 714–725, 2009.
372 L Reynolds, N Consedine, D A Pizarro, & I Bissett, 'Disgust and behavioral avoidance in colorectal cancer screening and treatment: A systematic review and research agenda', *Cancer nursing: An international journal for cancer care*, 36, 122–130, 2012, p. 3.
373 A Kolnai, *On disgust*, B Smith, C Korsmeyer (ed. and introduction), Open Court, Chicago and La Salle, Illinois, 2004, p. 25.

374 A Kolnai, *On disgust*, 2004, p. 76–78.
375 A Kolnai, *On disgust*, 2004, p 63.
376 A Kolnai, *On disgust*, 2004, p 47.
377 A Kolnai, *On disgust*, 2004, p 18.
378 David Pizarro in an interview, *To the best of our knowledge*, radio podcast, Yuck, 28.8.2016, 00:15:40 – 00:16:30, <http://www.ttbook.org/listen/92166>
379 Haidt et al., *Psychology and developing societies*, 1997, p. 109.

5.3. Abject and uncanny

One key aspect of Kristeva’s abject is that it questions the borders of definitions, threatening to tear down the whole structure. As noted before, Menninghaus sees abject as just another word for disgust and Krauss compares abject with Sartre’s slimy. This section looks at uncanny in relation to abject, as they both tackle the same question with regards to why some things disturb people.

In 1919, Sigmund Freud felt, in his own words, compelled to ‘investigate the subject of aesthetics’.³⁸⁰ In his essay *The Uncanny* (unheimlich) Freud examines the phenomenon by tracing the literary definitions of it and by looking at the actual things or stories people find uncanny. Freud’s essay is usually the academic starting point for examining uncanny.

However, it was not the first essay on the subject. Freud’s own starting point was Dr. Ernst Jentsch’s text *On the Psychology of the Uncanny* written in 1906. (Translated to English in 1995.) In the essay, Jentsch does not define the essence of uncanny, but tries to find an adequate working definition. The reason why Jentsch is reluctant to look for an actual definition is because he acknowledges that what feels uncanny to one person does not necessarily feel uncanny to another. For Jentsch uncanny is something that defies the intellectual mastery of one’s environment:

‘Intellectual certainty provides psychical shelter in the struggle for existence. However it came to be, it signifies a defensive position against the assault of hostile forces, and the lack of such certainty is equivalent to lack of cover in the episodes of that never-ending war of the human and organic world for the sake of which the strongest and most impregnable bastions of science were erected.’³⁸¹

Jentsch concentrates on concrete physical situations, and states that the strongest of these physical uncertainties is that of not knowing whether or not an object is alive. According to Jentsch, the uncomfortable feeling will last until the issue of living or not living is resolved. He also brings up that although people usually do not want to feel uncanny in real situations, in theatre and literature uncanny can become a vessel of artistic pleasure.³⁸²

Freud starts with Jentsch’s text with a determination to define the uncanny and to explain it. He concludes that the uncanny feeling appears when

380 S Freud, *The uncanny*, London. Penguin Books, (Orig. Das Unheimliche.) 1919, p. 1.
381 E Jentsch, ‘On the psychology of the uncanny’, *Angelaki* 2:1, 7–16. (Orig. 1906), 1997, p. 15.
382 E Jentsch, *Angelaki*, p. 11–12.

something we have believed to belong only to the imaginary appears in real life, for example when a doll moves on its own or when the dead become alive. Or, in addition, when something that has been hidden and repressed emerges: ‘[T]he “uncanny” is that class of the terrifying which leads back to something long known to us, once very familiar.’³⁸³

Academic Nicholas Royle, who traces the history of uncanny from 1850s to the present in his book *The Uncanny* (2003), rephrases Freud’s idea: ‘The uncanny involves feelings of uncertainty, in particular regarding the reality of who one is and what is being experienced.’³⁸⁴ Royle, like Jentsch, bring up that the uncanny is not only about terrible things:

‘But it can also be matter of something strangely beautiful, bordering ecstasy (‘too good to be true’), or eerily reminding us from something like déjà vu.’³⁸⁵

Although Royle examines uncanny in great detail, he mostly concentrates on how literature can bring forth the uncanny and neglects the link to physical reality. He does mention though that sight and seeing are central to the uncanny, although other senses can play a role too.³⁸⁶

Freud underscores in his essay that there is also a condition for fiction to be uncanny: ‘so long as the setting is one of physical reality; but as soon as it is given an arbitrary and unrealistic setting in fiction, it is apt to lose its quality of the uncanny.’³⁸⁷ Freud explains this by using Hans Christian Andersen’s stories as an example. In his stories, a tin soldier and a piece of furniture come to life, but they still don’t bring forth an uncanny feeling. However, when one sees a ghost in her or his bedroom or reads about a wood table turning into an animal at the neighbour’s house, the uncanny feeling emerges. In other words, for something to become uncanny it needs to have a link to physical reality – this does not mean only a real experience in the physical world but also that literature and for example photographs can provide the link. This link to physical reality is the key when applying the concept to photographs.

383 Freud, *The uncanny*, 1919, p. 1–2.
384 N Royle, *The uncanny*, Manchester, Manchester University Press 2003, p. 1.
385 N Royle, *The uncanny*, 2003, p. 2.
386 N Royle, *The uncanny*, 2003, p. 45.
387 Freud, *The uncanny*, 1919, p. 19.

5.3.1. Uncanny proximity of photographs

One simple way to look at photography as the physical link for the uncanny feeling is through proximity, more precisely the proximity between the image and its viewer. Proximity by definition means nearness in space, time or relationship. First, photographs are compared against physical reality. At least at first glance. A good example is Thomas Demand’s photographs, in which he recreates spaces by building them from styrofoam, paper and card, and then photographing the constructions. Demand’s photographs look like real spaces, or often they are assumed to be so, at first glance; they feel uncanny.

Secondly, photographs carry the sense of time (and history) with them; they refer to specific moments in the past whether it is seconds or decades. A photograph taken by a surveillance camera has a direct link not only to the place but time. Thirdly, photographs feel emotionally close because of the relationship viewers have with them. Susan Sontag notes that people don’t throw away or tear photographs of their loved ones.³⁸⁸ Also W.J.T. Mitchell writes about his colleagues’ experiment in which students were asked to take a photograph of their mother and cut the mother’s eyes out; the students were reluctant to do it.³⁸⁹ Thus, despite a photograph being a representation, it still seems to somehow embody what it is depicting.

In photography research W.J.T. Mitchell, who has conceptualised images as living agents, points out that there are two ways in which images can be alive (and disturbing): either because the viewer believes (similar to religious belief) that the image really is alive or because the image appears to be alive because it is either a trick or an automaton (puppetshows and animation), and the uncanny appears in the space in between, in the uncertainty.

‘Thus the notion of image as life-forms always equivocates between questions of belief and knowledge, fantasy and technology, the golem and the clone. This middle space, which Freud called the Uncanny, is perhaps the best name for the location of images as media in their own right.’³⁹⁰

If for Mitchell images are alive, for Roland Barthes all photographs are zombies: ‘that rather terrible thing which is there in every photograph: the return of the dead’.³⁹¹ For Barthes photography is inseparable from its relation to death, which is also the Eidos of photographs:

‘it is because it certifies, so to speak, that corpse is alive, as corpse: it is the living image of a dead thing. For photograph’s immobility is somehow the result of a perverse confusion between two concepts: the Real and the Live [...]’³⁹²

When examining uncanny in relation to photography, it is not just that photography as a medium is uncanny, but that the representation can have uncanny elements making the whole representation uncanny. Slavoj Žižek writes that: ‘alteration of a small detail in a well-known picture that all of a sudden renders the whole picture strange and uncanny.’³⁹³ This formulation resembles Roland Barthes’ definitions of studium and punctum. The studium is ‘that very wide field of unconcerned desire’, and the punctum is something in a photograph that pierces and bruises.³⁹⁴ When we consider uncanny in a larger sense, including déjà vu for example, it has the very same characteristics as the punctum – it, too, pierces and bruises.

Many researchers in different fields have tried to outline not just how but why the uncanny feeling appears, especially in relation to photographs, animations and robots. Japanese professor Masahiro Mori wrote an essay titled *The Uncanny Valley* in 1970s in which he drafted a curve of the emotional response to humanlike robots. The text appeared originally in a Japanese journal, but only after it was translated into English did it start to gain more attention in the early 2000s. In Mori’s curve, affinity towards robots increases until to the point when the robot starts to resemble a real human too closely and then turns into something eerie. Mori named this drop in the curve the uncanny valley.³⁹⁵ At the bottom of the valley are for example zombies and dead bodies. Mori speculates that the feeling of eeriness is an instinct that ‘protects us from proximal – sources of danger.’³⁹⁶ By proximal sources of danger Mori means, for example, members of different species in addition to the corpses. Mori’s goal was to make robots acceptable to humans without making them eerie. He also wished that the mapping of the uncanny would explain what it is to be a human.

388 S Sontag, *On photography*, Picador. Farrar, Straus and Giroux, New York, (orig. 1977), 2011, p. 161.
389 W J T Mitchell, *What do Pictures Want? The lives and loves of images*, The University of Chicago Press Ltd., London, 2005, p. 9.
390 W J T Mitchell, *What do pictures want?*, 2005, p. 295.

391 R Barthes, *Camera lucida*, 1981, p. 9.
392 R Barthes, *Camera lucida*, 1981, p. 79.
393 S Žižek, *Looking awry. An introduction to Jacques Lacan through popular culture*, The MIT Press, London 1991, p. 53.
394 R Barthes, *Camera lucida*, 1981, p. 27.
395 M Mori, ‘The Uncanny valley’, *IEEE, Robotics & Automation Magazine*, Vol 19, Issue 2, 2012, p. 98–100.
396 M Mori, *IEEE, Robotics & automation magazine*, 2012.

The academic Catrin Misselhorn has gathered empirical data on and investigated philosophically into, why there is an uncanny valley. She comes to the conclusion that the eeriness stems from the so-called ‘failed concept application’ when perceiving things. By this she means that some features of the inanimate object bring forth the phenomenological feel of a human being, but this off-line feeling does not get applied into the final perception.

‘This reminds a bit of a radio receiver trying to tune into a transmitter in bad conditions when the reception of one station is always interfered with by another one and sheer noise.’³⁹⁷

Researcher and founder of Hanson Robotics, Ltd. David Hanson suggests that when a robot or another object appears very human-like, we start to criticise it with the same measurements we would normally apply to actual humans, and that is where the robot fails and becomes something unwanted and eerie.³⁹⁸

However, this happens only when we confuse the robot with a human. David Hanson et al. pinpoint in another article that in the arts, the quality of human resemblance, for example in Ron Mueck’s realistic, but oversized human sculptures, is praised and aesthetically valued. Hanson et al. also performed web-based tests. In one of the experiments, the researchers showed videos of two human-looking robots simulating human expressions and asked if people found the robots eerie. None of the participants were disturbed by the appearance of the robots, despite the fact the participants also answered that the robots look very lively. In addition, 73 percent found the robots also appealing.³⁹⁹ Therefore, Hanson et al. propose that the uncanny valley should be upended because of the counter-examples found in the arts and in their own experiments.

One tentative explanation as to why the uncanny valley might not hold as proposed by Mori is time. Mori wrote his essay in 1970s, whereas now, people are perhaps more accustomed to idea of human-like robots, because they have seen photographs or videos of androids, read books or watched TV series or movies about androids. The idea of an android is contemporarily more imaginable; we are more accustomed to the idea. At the Miraikan Museum in Tokyo, there are three androids, and one of them

is the teleoperated Otonaroid. The robot engages with the audience by talking and moving; for example the robot waves its hand and makes eye contact. When I visited the museum in Tokyo, especially children seemed to be keen to interact and engage with Otonaroid.

Both uncanny and abject operate within definition systems. By definition a doll is not supposed to move on its own, and when it does, it is disturbing. (A robot is supposed to move, so there is necessarily nothing eerie about a moving robot.) The main difference is that uncanny acknowledges that something is not like it is supposed to be whereas abject questions this whole being. Also, the uncanny feeling disappears when the doll is revealed to be a robot or when it is seen that the movement is caused by wind, while, by contrast, abject has no quick or easy resolution. Misselhorn bluntly concludes that the uncanny valley has something to do with ‘the terrors of death’.⁴⁰⁰ Abject on the other hand is more of an existential crisis. When the task is to apply the concept of abject or uncanny to actual photographs, it is essential to bear in mind that for something to become uncanny it needs to have a link to physical reality. Later in this chapter I propose that also this link to physical reality is why art photographs can be uncanny and/or abject. The next section looks at abject art.

5.4. Abject art

Kristeva’s book on abject has inspired both artists and curators, especially in the 1990s. Three exhibitions in the same year, 1990, set the tone for abject art according to Artforum editor Michael Wilson. He states that *Just Pathetic* at Rosamund Felsen Gallery in Los Angeles, *Work in Progress?* Work? at Andrea Rosen Gallery and Vik Muniz’s *Stuttering* at Stux Gallery in New York outlined how abject art would be defined and understood.⁴⁰¹ Also in 1990, the Swedish curator Gertrud Sandqvist curated an exhibition entitled *Abject* at Galleri Enkehuset in Stockholm and at the Nordic Art Centre in Helsinki, Finland. Sandqvist chose to exhibit only works made by female artists, as she wanted to highlight the feminist qualities of abject art. Among the artists were Eija-Liisa Ahtila, Cecilia Edelfalk and Nina Roos.⁴⁰²

In 1993, the Whitney Museum in New York City held the exhibition *Abject Art*. One of the pieces in the exhibition was Todd Alden’s *Collectors’ Shit*, which consisted of sealed containers of art collectors’ faeces. The *Abject*

397 C Misselhorn, ‘Empathy with inanimate objects and the uncanny valley’, *Minds & Machines* 19:345–359, 2009, p. 357.

398 D Hanson, ‘Expanding the aesthetic possibilities for humanlike robots’ In Proc. IEEE Humanoid Robotics Conference, special session on the uncanny valley, Tsukuba, Japan, 2006.

399 D Hanson, A Olney, I Pereira, M Zielke, ‘Upending the uncanny valley’. Conference paper: Proceedings, the twentieth national conference on artificial intelligence and the seventeenth innovative applications of artificial intelligence conference, July 9-13, 2005, Pittsburgh, Pennsylvania, USA. p. 24-31, 2005. p. 29–30, <https://umdrive.memphis.edu/aolney/public/publications/Upending%20the%20uncanny%20valley.pdf>

400 C Misselhorn, *Minds & machines*, 2009, p. 357.

401 M Wilson. ‘Michael Wilson on sore winners’, *Artforum* 43 no.2, October 2004. p 117–118.

402 J Steihaug, *Abject/Inform/Trauma: discourses on the body in american art of the nineties*, *For art*, 1995, p. 20, 39. Accessed Oct 25, 2016, http://www.forart.no/index2.php?option=com_iarticles&no_html=1&Itemid=22&task=file&id=144

Art exhibition included bodily fluids and anatomical body parts, as the curators wanted to imply the psychoanalytic theory of abject and test the borders of the art institution. Art history researcher Joseph Henry quotes the curators' statement in the exhibition catalogue: 'our goal is to talk dirty in the institution and degrade the atmosphere of purity and prudery'.⁴⁰³

Art historian and critic Hal Foster explains the fascination with abject in the early 1990s with the then current social conditions: AIDS, poverty, crime and the collapse of the welfare state:

'a special truth seems to reside in traumatic or abject states, in diseased or damaged bodies. To be sure, the violated body is often the evidentiary basis of important witnessing to truth, of necessary testimonials against power.'⁴⁰⁴

According to Foster, the avant-garde artists and writers of the time were attracted to abject because of their desire to disturb the structures of society and individuals. Likewise, the curator and art historian Joseph Henry sees that Kristeva's theory responded to a specific historical moment. According to him, abject gave the means to the curators to comment on the political climate of the time and address for example gender and AIDS issues.⁴⁰⁵

Hal Foster sees that abject art has branched in two directions: to those that wish to be abject and touch the actual wound, and to those that wish to unveil the operation of abjection 'to catch abjection in the act'.⁴⁰⁶ However, Foster criticises the application of a theoretical concept to actual works of art and asks:

'Can the abject be represented at all? If it is opposed to culture, can it be exposed in culture? If it is unconscious, can it be made conscious and remain abject? [...] Can abject art ever escape an instrumental, indeed moralistic, use of the abject?'⁴⁰⁷

In a different vein, Joseph Henry's detailed analysis of the abject art movement ends with him calling for a critical art movement that would not need an academic theory to back it up.

Regardless of how close the unison between the theory and the actual works was and is, since the 1990s abject art has evolved into a term that is used to describe a broad variety of works, ranging from Kiki Smith's use

of menstrual blood to Cindy Sherman's photographs that combine dolls, filth and pimples. Joseph Henry also refers to 'abjection as an aesthetic technique'.⁴⁰⁸ For this, he takes as an example Kara Walker's installation piece *Creative Time*, a sculpture depicting a sphinx-like woman coated with sugar, which melted into a bad-smelling and horrendous-looking pile of matter in the course of its exhibition.

The philosopher Carolyn Korsmeyer, who has researched aesthetics and emotion theory, offers an explanation to why artists and curators have been interested in the concept of abject. According to her, disgust is a powerful way to make the viewer linger, and that disgust may turn into attraction.⁴⁰⁹ Furthermore, Winfried Menninghaus writes that artists have taken advantage of disgust, which is the strongest human sensation, for centuries and continue routinely to do so.⁴¹⁰

Artworks can produce visceral responses, as Diane Gromala argues in her book *Towards a Phenomenological of the Visceral in the Interactive Arts*. By visceral she means 'respiratory, cardiovascular, uro-genital and especially enteric (or excretory) systems'⁴¹¹. In Gromala's own work, the viewer's monitored heart rate and breath rate affect the actual encounter with the artwork. Gromala claims that abjection is merely one small aspect of the visceral spectrum; yet it often accounts for the strongest responses. Gromala used rotting meat in her *Meat book* piece to disturb viewers. The physical reactions of disgust can include for example wincing, slowing of the pulse, blinking and a galvanic skin response.⁴¹²

For Korsmeyer, disgust is not just a single, and always similar, physiological reaction, but has a lot of variations from subtle to strong.⁴¹³ Even though Korsmeyer writes that disgust is 'grounded in beliefs embedded in cultural values', she does not want to abandon the reflex character of disgust entirely either.⁴¹⁴ Korsmeyer speculates that: 'Perhaps the slower pulse marks a tendency for disgust to make us pause over its object, to savor it with loathing'.⁴¹⁵

According to Korsmeyer disgust has been neglected as a possible emotion leading to art apprehension. For her the aesthetic disgust does not arouse the sublime – which in aesthetics has been seen as the strongest

403 J Henry, 'The suffering body of 1993: whatever happened to the "Abject", Part II', *Momus*, April 28, 2015, accessed Nov 8, 2016, momus.ca/the-suffering-body-of-1993-whatever-happened-to-the-abject-part-ii/

404 H Forster, 'Obscene, abject, traumatic.' *October* 78, 1996, p. 122–123.

405 J Henry, *Momus*, 2015.

406 H Foster, *The return of the real*, 1996, p. 157.

407 H Foster, *The return of the real*, 1996, p. 156.

408 J Henry, *Momus*, 2015.

409 C Korsmeyer, *Savoring disgust, The foul and the fair in aesthetics*, Oxford University Press, 2011, p. 11.

410 W Menninghaus, *Disgust. Theory and history of a strong sensation*, State University of New York Press: Albany, 2003, p. 12.

411 D Gromala, *Towards a phenomenological theory of the visceral in the interactive arts*, Plymouth, University of Plymouth, 2005, p. 47.

412 Korsmeyer, *Savoring disgust*, 2011, p. 24.

413 Korsmeyer, *Savoring disgust*, 2011, p. 88.

414 Korsmeyer, 2011, p. 22.

415 Korsmeyer, 2011, p. 37.

and highest awe art can produce – but sublate: ‘just as fear can be the foundation for encounters with the sublime, so disgust can achieve its own aesthetic counterpart [...] the “sublate”.’⁴¹⁶ Korsmeyer borrows the term from chemistry where it has been used to mean something turning from gas directly to solid, whereas sublimate in chemistry means something turning from solid to directly to gas. Fundamentally, Korsmeyer’s sublate functions the same way as sublime: an experience of a strong emotion (fear or disgust) turns into apprehension, but when fear and terror can make a person feel small or powerless, disgust contaminates, disintegrates the body and individuality, and furthermore disgust can slowly sneak in.⁴¹⁷ The workings of ‘fear’ in art viewing was tested in a study conducted in Brooklyn, New York. Researchers found out that inducing fear made people appraise abstract art more positively than without. Inducing happiness did not work the same way.

‘Our data suggest that art’s allure may instead be a byproduct of one’s tendency to be alarmed by such environmental features as novelty, ambiguity, and the fantastic. Artists may be tapping into this natural sense when their work takes people’s breath away.’⁴¹⁸

Negative emotions, like disgust and fear, have largely been ignored in theories of aesthetic emotions; in fact, major theories ‘cannot in principle explain emotions like anger and disgust.’⁴¹⁹ Psychologists Paul Silvia and Elizabeth Brown note that many researchers limit aesthetic emotions to include only positive emotions. They write that negative emotions are at the centre of censorship and conflicts, and artists do also try to deliberately evoke negative feelings in their audiences. ‘To be credible, a psychology of aesthetics must have something to say about how this works.’⁴²⁰

One negative emotion that can be evoked in images and more precisely in photographs is disgust. The next section examines the concept of abject in relation to photography and to photographs depicting sickness.

416 Korsmeyer, 2011, p. 131.

417 Korsmeyer, 2011, p. 134–135.

418 Eskine, Kendall J.; Kacinik, Natalie A.; Prinz, Jesse J.: ‘Stirring images: Fear, not happiness or arousal, makes art more sublime.’ *Emotion*, Vol 12(5), Oct 2012, 1071–1074. 2012, p. 1073.

419 P J Silvia & E M Brown, ‘Anger, disgust, and the negative aesthetic emotions: Expanding an appraisal model of aesthetic experience’, *Psychology of aesthetics, creativity, and the arts*, 1, 100–106, 2007, p. 100.

420 P J Silvia & E M Brown, ‘Anger, disgust, and the negative aesthetic emotions: Expanding an appraisal model of aesthetic experience.’ *Psychology of aesthetics, creativity, and the arts*, 1, 100–106, 2007, p. 105.

5.5. Applying abject and photography

The reason for introducing abject in this research was a hope that it could help in explaining why some photographs are ‘too much’, why the viewer sometimes wants to turn away and at the same time peek again. This chapter addresses the question introduced in chapter two: Why is it so uncomfortable to look at photographs that represent sickness or suffering? In other words why does a photograph depicting sickness sometimes show too much, to the extent that the viewer turns his or her gaze away – sometimes only to return to linger with fascination. To this end, I am addressing two series of works: Max Aguilera-Hellweg’s photographs of invasive surgeries and my own photographic series of disease-related removals.

5.5.1. Systems and their borders

In the example at the beginning of the chapter, the man at the gallery seemed to be in a state of unease because of a photograph of a gallstone. For Kristeva, the reaction to confronting abject, spurs from culture. She points out that laws and religions base their functions on prohibiting filthy, defiling elements. Defilement is jettisoned from symbolic systems and it escapes both social rationality and logical order. According to Kristeva, what makes confronting the abject so disturbing is the thought that maybe there is no ‘clean self’ at all.⁴²¹ Kristeva frames the thought: ‘It is as if the skin, a fragile container, no longer guaranteed the integrity of ones’ “own and clean self”’.⁴²² Accordingly, a gallstone outside of the body is disturbing because it is external to a body that people would like to think is whole and intact.

However, there are no universal things that are dirty or defiling for everyone, as Mary Douglas writes in *Purity and Danger*. She stresses: ‘that there is no such thing as dirt; no single item is dirty apart from a particular system of classification in which it does not fit.’⁴²³ In other words, defilement and dirt only exist if there is a system that excludes them, which makes the system a precondition for abject.

In making the *Removals* series, in which I photographed removed tumours, gallstones and cancers at two hospitals in Tampere, there was no abject experience for me. I think this was because I was so focused and intrigued

421 Kristeva, *Powers of horror*, 1982, p. 65.

422 Kristeva, *Powers of horror*, 1982, p. 53.

423 M Douglas, *Purity and danger*, Routledge, London and New York, 2002, p. XVII.



Max Aguilera-Hellweg: *Exposed spinal cord*, in *The Sacret Heart*, 1997.

by how the removed tumors looked and too occupied with making the picture; most of the time, I had only a few minutes to take the photograph before the tumour would be sent to examination.

One time in the hospital in Tampere, while getting ready to take a photograph of the removed gallstone in the corner of the room, an operating room nurse refers to me half-jokingly as a ‘pervert’. She adds that it is unnatural to value filth. However, Kristeva argues:

‘The abject is perverse because it neither gives up nor assumes a prohibition, a rule, or a law; but turns them aside, misleads, corrupts, uses them, takes advantage of them, the better to deny them.’⁴²⁴

Kristeva’s idea is that the abject and abjection refuse to obey cultural prohibitions or laws, and question borders as such, regardless of whether the border is between life and death, inside and outside, mother and father, or nature and culture. Abject compromises the very borders of our own body and identity, which is the disturbing part. In other words, abject questions the borders that ultimately constitute us.

Confrontation with a symbolic border is emphasised in Max Aguilera-Hellweg’s book *The Sacred Heart, An Atlas of the Body Seen Through Invasive Surgery*. The book, made in 1997, contains detailed photographs of invasive surgeries shot by a 4 × 5 inch large-format camera, which accounts for the richness of the details in the photograph. Aguilera-Hellweg writes in his book about his experiences when taking the photographs:

‘I realized I was in the presence of the most intimate, most vulnerable, most inviolate thing I had ever seen. The spinal cord had never seen light, wasn’t meant to see light, and at this moment was bathed in light. My first impulse, I must confess, was to spit. To defile it in some way. Bring it down to my level. I didn’t of course, but I felt I was in the presence of something so precious, so amazing, so powerful, so pure. I couldn’t bear the intensity:
“What is it?” I asked. “What is it made of?”
“It is like a sausage,” the surgeon said, “with toothpaste inside.”’⁴²⁵

Aguilera-Hellweg writes that he wanted to defile the pure. For him, the disturbing part was the spinal cord outside of its normal context and its symbolic order. Similarly, the French photographer Raphaël Dallaporta says in Chapter Three that the heart removed during the autopsy was not supposed to see light.

424 Kristeva, *Powers of horror*, 1982, p. 15.
425 M Aguilera-Hellweg, *The Sacred Heart. An atlas of the body seen through invasive surgery*, Bulfinch Press, Hong Kong, 1997, p. 40.

Umberto Eco contemplates where beauty stops in *The Name of the Rose*:

‘The beauty of the body stops at the skin. If men could see what is beneath the skin, as with the lynx of Boeotia, they would shudder at the sight of a woman. All that grace consists of mucus and blood, humors and bile. If you think of what is hidden in the nostrils, in the throat, and in the belly, you will find only filth. And if it revolts you to touch mucus or dung with your fingertip, how could we desire to embrace the sack that contains that dung.’⁴²⁶

In psychological research, skin as a border between the inside and outside of ‘self’ has been examined by Paul Rozin and April E. Fallon. According to them, the biological ‘bodily self’ is roughly bordered with skin, and the mouth is the most charged border between self and non-self.⁴²⁷ For example, saliva and other bodily fluids are acceptable as long as they are within the borders of the self, but as soon as they are outside, they become disgusting. To put in an everyday context, think about eating soup: in one’s mouth the soup will be mixed up with saliva, swallowed and incorporated into one’s system. What if one would have spat in the soup before eating it? Rozin and Fallon conducted a small study where they asked people to rate how much they liked a bowl of soup versus the same bowl of soup after the participants had themselves spat in their own soups. The result showed that the ratings dropped with 49 of the 50 subjects.

This result made Rozin and Fallon speculate where exactly is the border: ‘[...] if the tongue is extended, with chewed food on it, is it acceptable to return the food to the mouth, or has it passed into the outside world.’⁴²⁸ The border of the ‘self’ is not necessary fixed but rather a fluid state, for example a mother’s reaction to her infant’s faeces or lovers’ loss of disgust to each other’s body odours and sexual fluids: ‘these intimate relations may weaken disgust by blurring the self-other distinction.’⁴²⁹ Paul and Rozin are concentrating on disgust in a very concrete sense in their article, but their thoughts still connect with Kristeva’s writings about abjection where the borders of the body and identity become questioned and contested on a more abstract level.

Aguilera-Hellweg was disturbed but fascinated by the things he saw. After eight years of working on the project, he enrolled at medical school to become a doctor, but later returned once more to photography and art. In addition to his artistic works, Aguilera-Hellweg has photographed sick children, doctors, and various medical conditions, for a number of international magazines.

426 U Eco, *The name of the rose*, Warner Books Inc., New York, 1986, p. 195.
427 Rozin, Fallon, *Psychological review*, 1987, p. 26.
428 Rozin, Fallon, *Psychological review*, 1987, p. 26.
429 Rozin, Fallon, *Psychological review*, 1987, p. 38.

Why did Aguilera-Hellweg want to share the photographs of invasive surgeries with other people? For, he had realised early on that he could not show his photographs to just anyone: a woman had broken into tears and a photo editor had gone white. Richard Selzer writes in the prologue of Aguilera-Hellweg's book: 'It is not the beautiful or the sublime that is celebrated here; it is the forbidden, the truth incarnate before which even a physician's heart may quail.'⁴³⁰ Aguilera-Hellweg writes that he wanted to continue his project for those people who could not bear to look at them: 'I hoped to provide a visual text by which one might become less afraid of the body, medicine, and, ultimately, less afraid of death'.⁴³¹

In the epilogue of the Aguilera-Hellweg's book, A.D. Coleman notes that confronting the images was for him 'a form of existential free fall',⁴³² which is something that Kristeva also writes on:

'My body extricates itself, as being alive, from that border. Such wastes drop so that I might live, until, from loss to loss, nothing remains in me and my entire body falls beyond the limit – cadere, cadaver.'⁴³³

In this existential experience Korsmeyer sees the very potentiality of aesthetic disgust: 'It teases consciousness and the limits of tolerance, and it acquaintances us with the common determinant of organic life and eventual loss of identity.'⁴³⁴ For her, herein lies the potential of disgust to transform into pleasure as it loses its aversive features. According to Korsmeyer, the possible residue, remaining from the once disgusting features, deepens the experience of the encounter.⁴³⁵ The philosopher Filippo Contesi objects to Korsmeyer's way of linking disgust to mortality and to the transition of life and death. Contesi sees that this can indeed be the case with some things that elicit disgust, but not with all. As an example, Contesi uses moral disgust. However, Contesi is unable to deny that there could be aesthetic value in disgust.⁴³⁶

When photographs of removed breast cancer tissue or open surgery wounds throw people off balance, and ask them to question their body image, how do they cope with these feelings? The cultural historian Sander L. Gilman argues in his book *Disease and Representation: Images of Illness from Madness to AIDS* that the Western way to cope with the fear of a disease, of collapse and dissolution, is to project in onto the world, by locating and domesticating it. He writes that once we locate our fear we become whole again:

430 M Aguilera-Hellweg, *Sacred heart*, 1997, p. 13.

431 Aguilera-Hellweg, *Sacred heart*, 1997, p. 78.

432 Aguilera-Hellweg, *Sacred heart*, 1997, p. 113.

433 Kristeva, *Powers of horror*, 1982, p. 3.

434 Korsmeyer, *Savoring disgust*, 2011, p. 130.

435 Korsmeyer, *Savoring disgust*, 2011, p. 87.

436 F Contesi, 'The meanings of disgusting art', *Essays in philosophy*. Vol. 17: Iss. 1, Article 5, p. 68–94, 2016, p. 84.

'then it is not we who totter in the brink of collapse but rather the Other. And it is an Other who has already shown his or her vulnerability by having collapsed.'⁴³⁷

This Other becomes the saviour, and the state of the person's uneasiness and disgust seems to be determined by how close to one the Other seems to be. How familiar does the skin look? How similar does the hand appear to one's own? There is a difference between a gallstone removed at the local hospital and an open surgery wound, which has been photographed on the other side of the world, in an exotic country. The man at the TR1 gallery came from Tampere, from the same city in which the gallstone and breast cancer were photographed. Whether he had had a gallstone removed a year before, if it was his own gallstone he was looking at, remains unknown.

When considering the man's reaction at the gallery, it is noteworthy that he was disgusted only after he knew what was in the photograph (a gallstone instead of a peanut). This brings us to the question of a photograph's inherent qualities and to the question of representation. One solution is to differentiate between a picture and an image as W.J.T. Mitchell does.⁴³⁸

Mitchell is a scholar who is devoted to critical theory in the arts. According to Mitchell, a picture is the physical and material thing on the gallery wall, whereas an image is the visual and mental formation of the thing in question. Accordingly, as he points out, we do not need to see a physical picture to be appalled by the image of it.⁴³⁹ He uses as an example Chris Ofili's painting *The Holy Virgin Mary*, which is partly made out of elephant dung. People were offended by the painting on the basis of its description. Korsmeyer notes that, in a similar manner, people can be really disgusted 'even when we know the intentional object of disgust is a fiction'.⁴⁴⁰ When it comes down to it, is Barthes' punctum or Lacan's tuché in the picture or not? Hal Foster interprets that:

'This confusion about the location of the rupture, tuché, or punctum is a confusion of subject and the world, inside and outside. It is an aspect of trauma; indeed it may be this confusion that is traumatic'.⁴⁴¹

Although we do not need a physical picture to be able to react to an image, a picture is often the precondition for the image to be possible, for the image to become abject. Next I will concentrate on how a photograph can be abject.

437 S L Gilman, *Disease and representation*, 1988, p. 73.

438 W J T Mitchell, *What do pictures want?*, 2005, p. 85.

439 Mitchell, *What do pictures want?*, 2005, p. 140.

440 Korsmeyer, *Savoring disgust*, 2011, p. 56.

441 H Foster, *Return of the real*, 1996, p. 134.

5.5.2. A photograph as abject

This section examines the photograph’s ability to induce abject in practice. I propose that photographs are potent in their ability to become abject because of their proximity. Aurel Kolnai drafted already in 1929 that for an object to appear disgusting there has to be ‘substantial proximity’ to the perceiver. By this he means: ‘proximity as sensual perceivability, as palpability, as the closeness of functional relation, traffic, communion with the object.’⁴⁴² Susan Sontag compares in her book *On Photography* her experience of seeing a real three-hour surgical operation in China, where nine-tenths of a man’s stomach was removed, to Antonioni’s documentary film *Chung Kuo*, where a less gory surgical operation is shown. Seeing the real surgery did not make Sontag flinch but the one in the movie did. Sontag points out two things. In a real situation, people can decide where and how they focus their gaze, while in photography and film it is not the case. Also film and photography condense time, so than an hours-long surgical operation lasts only a few minutes or just one exposure. According to Sontag, photography and film have the means to amplify the real⁴⁴³.

However, there are preconditions for a photograph to be abject. First, a system or a category is needed for abject to exist in the first place. By this I do not mean tangible characteristics of a photograph, but the underlying presuppositions rooted in each culture. This system can be for example the bodily self, divided by the skin into an outside and inside, or a categorisation between health and illness, or the division between nature and culture. However, borders are not always fixed but relatively fluid. Also, as Sontag writes, the act of photographing is to make something part of an information system because photography in itself is a tool for classifying.⁴⁴⁴

Secondly, an unsafe context prevents the viewer from feeling at ease. A photograph of an adult pissing on a table is easier to look at in a catalogue for an art performance in which the adult is pretending to be a dog than in a newspaper. Radley argues that a mundane context makes horror appear more effectively.⁴⁴⁵ Biernoff writes about blurring the line between art and medical images in her essay *Flesh Poems*, which explores Henry Tonk’s drawn portraits of the facial reconstructions of badly wounded soldiers. Biernoff states that these pictures draw attention to the ambivalent nature of the representational practices themselves.⁴⁴⁶ She points out that at the very moment when photographs of suffering or the diseased are shown beyond the medical context, ‘they begin to ask questions of us’

442 Aurel Kolnai, *On disgust*, 2004, p. 78.

443 S Sontag, *On photography*, 2011, p. 168–169.

444 S Sontag, *On photography*, 2011, p. 156.

445 Radley, *Works of illness*, 2009, p. 159–172.

446 S Biernoff, ‘Flesh poems: Henry Tonks and the art of surgery’, *Visual culture in Britain* 11.1., p. 25–47, 2010, p. 30.

and ‘confronts us with the limits of spectatorship, curiosity, understanding and empathy.’⁴⁴⁷ A photograph of an amputated leg is probably not so disturbing in a medical leaflet, or in a commercial for Halloween store, as it is on a gallery wall. However, whether an art gallery is an unsafe context depends on what kind of a system one thinks art gallery is.

In psychoanalytic terms, context could be seen as Hal Foster looks at Lacan’s screen. For Lacan, between the one who looks and the object that looks back there is an image-screen.

‘Call it the conventions of art, the schemata of representation, the codes of visual culture, this screen mediates the object-gaze for the subject, but it also protects the subject from this object-gaze [...] and tames it in an image.’⁴⁴⁸

Taming or numbing can also happen in the form of repetition as discussed in Chapter Two: smokers become accustomed to seeing detailed colour images of lung and mouth cancers on the side of their cigarette packets.

Thirdly, a feeling of proximity is needed for disgust to make its appearance: ‘the thing has been there.’⁴⁴⁹ Photographs’ indexicality is entwined with the knowledge of how they are made: rays of light reflected from the thing photographed reacting to a matter (film or sensor) and ‘it is this knowledge that makes it an index – not, therefore, the immediate experience of it,’ Francois Brunet argues.⁴⁵⁰ He wants to underscore that for a photograph to be able to represent its subject we need to know the way it has been made.

Finnish scholar Janne Seppänen, who has researched the ontology of photographs, summarises that a photograph does not just re-present something that was outside of it, but that this outside thing is also present in the photograph. According to him, this paradox makes the photographic representation blurry; the viewer does not really know which one he or she is experiencing, the thing photographed or its representation.⁴⁵¹ When researchers try to explain why photographs can evoke disgust or become abject, they often actually tangle with the question of the representation. It is often either the context of the photograph or its indexicality that gets highlighted, sometimes both.

447 Biernoff, *Visual culture in Britain*, p. 30.

448 H Foster, *Return of real*, 1996, p 140.

449 R Barthes, *Camera lucida: Reflections on photography*, Hill & Wang, New York, 1981.

450 F Brunet, “A better example is a photograph” On the exemplary value of photographs in C. S. Peirce’s Reflection on Signs’ in *The Meaning of Photography*, R Kelsey, B Stimson (eds.) Yale University Press, New Haven/ London, p. 34–49, 2008, p. 39.

451 J Seppänen, *Levoton valokuva*, Vastapaino, Tampere, 2014, p. 96.

For example, Alan Radley highlights that photographs of sickness are disturbing because ‘we are used to reading these as if they were direct quotes from reality’.⁴⁵² Likewise cultural theorist Suzannah Biernoff states: ‘photographs of suffering somehow contain or embody their subjects; and that they therefore carry a burden of care’.⁴⁵³ This ‘somehow’ remains unexplained.

Kristeva highlights the ambiguity of abjection, by saying that it: ‘does not radically cut off the subject from what threatens it – on the contrary, abjection acknowledges it to be in perpetual danger’.⁴⁵⁴ Danger is very present in eating a puffer fish, which Korsmeyer uses as an example. Puffer fish is a Japanese delicacy that remains highly toxic if not prepared in the right way. In the correct preparation of the fish, some of the neurotoxins are deliberately left in, so that the eater’s lips and tongue get numb, as a sweet reminder of the possible danger. Korsmeyer writes that this danger is said to make the eating of the puffer fish even more enjoyable. Perhaps a similar hint of reality (indexicality) is what makes horrible photographs such powerful images – and even enjoyable.

‘When I study these images, I feel like I am absorbing poison from their surface. Or, in one of Bataille’s own metaphors, they are like the sun: they actively hurt my eyes, they are hard just to see without wincing,’⁴⁵⁵ James Elkins writes about looking at the images of lingqi.

Lingqi (also lingchi), sometimes translated as ‘death by a thousand cuts’, is a Chinese torture and execution method whereby parts of the body are sliced away while the person is still alive. The images Elkins refers to, the same images about which Bataille writes in *Tears of Eros*, are black and white photographs taken in Beijing in 1905. The photographs are extremely hard to look at. For Elkins, these photographs, because it is unbearable to look at them, become essential to photography itself. He writes:

‘These photographs surround photography: they are at one limit of what photography is, at its boundary, and they are also, I think, at the very center of what photography is.’⁴⁵⁶

Despite the frequent interpretation that many scholars make about horrible photographs reminding us of our own mortality or bringing forth our fear of dying, it is maybe not death that haunts us but life, as philosopher Eugene Thacker suggests in his book *In the Dust of This Planet*. He reminds us that there is still no definitive philosophical answer to the question ‘what is life?’,

how we are to define it adequately.⁴⁵⁷ The disturbing and haunting part is perhaps exactly this unknowing, the arbitrary construction of a border.

In conclusion, both the photograph of a removed gallstone and the other of a surgical cut revealing the spinal cord have qualities to disturb (the lingqi photographs do more than disturb, they haunt), and these qualities enable them to become abject mainly because of their proximity. With these images, the viewer may encounter the limits of his or her being. Following Kristeva’s writings, what get contested are a clear-cut identity and the intact body image, as the border between outside and inside is destroyed.

In this chapter I have concentrated on images of open surgeries and removed body parts, on images that are difficult for many Western people, but not necessarily found repulsive in other cultures. In addition, there is a multitude of representations of sickness, many of which are less disgusting, less difficult. However, when contrasting how Kristeva defines abject and how Sander L. Gilman writes about how we look at representations of the diseased in general, they have a lot in common (and a common inspiration in Mary Douglas’s *Purity and Danger*): ‘How we see the diseased, the mad, the polluting is a reflex of our own sense of control and the limits inherent in that sense of control.’⁴⁵⁸

457 E Thacker, *In the dust of this planet. Horror of philosophy vol 1*, Zero Books, UK, 2011, p. 68.

458 S L Gilman, *Disease and representation*, 1988, p. 3.

452 A Radley, ‘Portrayals of suffering: On looking away, looking at, and the comprehension of illness experience’, *Body & society*, 8:1, 2002, p. 5.

453 S Biernoff, ‘Medical archives and digital culture’, *Photographies*, 5:2, 2012, p. 198.

454 J Kristeva, *Powers of horror*, 1982, p. 9.

455 J Elkins, *What photography is*, Routledge, New York and London, 2012, p. 189.

456 J Elkins, *What photography is*, 2012, p. 189.

6.

Discussion

To answer my research question, how is sickness represented in art photography, I will first summarise and contemplate on the new information provided by the diagram in Chapter Three, evaluate the diagram's usability, look at the new knowledge in relation to previous research, then consider the possible reasons for being disturbed by the images studied in Chapter Five, and finally discuss the shape artistic research has taken in this dissertation. I will also trace the development of my own artworks in relation to the theoretical research.

Applying anthropologist Arthur Kleinman's definitions of sickness, illness and disease to contemporary art photography works shows that the majority of the recent – that is, made during the last 20 years – Western art photography works are concentrated on illness experiences, as the diagram in Chapter Three shows. In addition to the abundance of illness stories, there are a number, although a minority, of photographic artworks taking a different point of view, either focusing on the institutional, historical or political aspects of sickness or representing disease objective-like.

The diagram I constructed from Arthur Kleinman's definitions is a tentative tool to evaluate artworks from the perspective of what they are trying to say in the context of culture and society, and what their main message is in relation to sickness. As a tool, the diagram made evident how hard it is to interpret artwork, as I had to reposition and rethink many of the artworks multiple times, and the diagram inevitably lead to stripping the artworks of other contemporary aspects and looking at them only through the frame of sickness, thus this perspective is a result of a conscious methodological choice.

The diagram allows artworks to be placed not exclusively under one category but between two, towards another or in the middle, which makes even subtle differences between the works more noticeable. In addition, all the works in the diagram are positioned in relation to each other, which also means that adding a new artwork could have the effect of demanding that the others must move relatively in the diagram. This makes the diagram time-consuming to use. Nevertheless, the diagram helped me to tweak differences and discern nuances of the artworks I would not have noticed otherwise.

In the beginning my aim was to make the diagram three dimensional, to add a timeline spanning the representations of health and sickness to death and beyond, as from the start it became evident that most artworks are made when the disease is already or is becoming life threatening. From all the works in the diagram, more than half address diseases that can be fatal. There are no works on the common cold, or other 'nuisances'. A timeline would offer a way to look at sickness more in detail in relation to the passage of time, which ultimately can also be seen as life itself, if we recall Merriam-Webster's definition of life as 'the period of time when

a person is alive.'⁴⁵⁹ In addition, as Thacker writes, if we look at life as a never-ending source, it morphs into another ultimatum, namely time.⁴⁶⁰ Time is also something that kept coming up in the artworks, for example Nan Goldin says in the introduction interview in the *Hospice* book: 'I realized that the only thing that separates me from the dying is time.'⁴⁶¹

This intertwining of time and corporeal life fascinated me when making *White Rabbit Fever* where I constructed two timelines. The first is a sequence of a rabbit decaying over a course of one hundred days, slowly dissolving into the surroundings, as I wanted to pose the question when a corpse stops being a corpse – at what point does it cease to exist? The second timeline presents sequences of four different biologically immortal (non-aging) cancer cells lines dividing and multiplying in a cell culture bottle and in microscopic sequences presented in books. One of the documented cell lines is the famous HeLa cell line, originating from an American woman Henrietta Lacks, who died in 1951. Her cancer cells are still growing and used in a variety of research; it is now estimated that her cells have been grown in the tens of thousands of kilograms.⁴⁶² Each cell has her DNA (although mutated).

Furthermore, a timeline could be a way to examine artworks from the point of view of health and illness co-existing, rather than opposing each other. This could reveal more nuances and differences in the artworks. However, adding the timeline to create a third dimension in the current diagram became too complex to retain accuracy. The solution could be to include fewer artworks in the diagram.

Stripping the diagram down to its very basics, what it does, is the following: it takes a structure (sickness) and divides it into three variables, with each tip of the triangle representing the most concentrated value of one of the three variables. Points inside the triangle represent mixtures of the three variables. On the basis of my experience using the diagram it could be applied to other themes as well, for example sex / gender / experience of sex/gender could tentatively work. Another perspective and a suggestion for further study would be to analyse the representations of sickness in relation to representations of the human body in general. This kind of analysis could reveal patterns and aesthetic choices that this research has not.

459 Merriam-Webster online dictionary, accessed 29.12.2015, <http://www.merriam-webster.com/dictionary/life>

460 E Thacker, *After life*, The University of Chicago Press, Chicago and London, 2010, p. 27, 29.

461 D Andre, P Brookman, J Livingston (eds.), *Hospice, A photographic inquiry*, Corcoran Gallery of Art and the National Hospice Foundation. A Bulfinch Press Book, Little Brown and Company, Boston, New York, Toronto, London, 1996, p.52.

462 L Margonelli, "Eternal life", *New York Times*, Feb 5, 2010, New York, accessed May 3, 2014, www.nytimes.com/2010/02/07/books/review/Margonelli-t.html?pagewanted=all&_r=0

6.I. Autopathographies

Kleinman defines sickness as a blanket term that contains political, economic, and institutional power structures, disease as a biological dysfunction, and illness as the culturally constructed experience of being sick. Applying these definitions to photographic artworks about sickness, my diagram shows that the majority of Western contemporary photography artworks on sickness approach the theme through illness experience. In more than thirty of them, the main message is to express the experience of being ill. This is almost half of all the works (67). There are at least three reasons that can help to explain this tendency. First, as the philosopher Havi Carel proposes, illness can have a significant philosophical role in a person's life because illness radically changes the way we experience our bodies, environment, relationships and time; illness is 'a compulsive invitation to philosophize.'⁴⁶³ This could be one of the reasons why artists have felt compelled to create art about or around their own or their family member's illness. Thomas Couser calls these personal narrative works on illness autopathographies.

For example, photographer Nancy Borowick writes in the statement of her series: 'One can only truly understand and appreciate life when faced with one's own mortality.' Similarly, photographer Ruth Adams writes that her images aim to show: 'that the journey can be one of physical and spiritual recovery instead of a spiral into illness and despair.'⁴⁶⁴ In addition, and secondly, as the medicalised society concentrates on the biological body and fixing its measurable dysfunctions, there is a vacuum for artists to explore and represent the neglected illness experience, the experience of which researchers have no consensus on what it is like.⁴⁶⁵

However, even if 'a compulsion to philosophize' would encourage artists to make art about their sickness in general, it does not explain why they place themselves or their close relatives in the photographs. This is the case in the majority of the illness stories in my diagram (24 out of 32). For a photography artist who regularly uses her or his own body in art, such as Mark Morrisroe, this seems natural, but what about all the other artists? They could just as well not show their body, or photograph someone else's body.

A possible explanation can be traced to the critique which representations of suffering faced especially in 1980s. In a nutshell, portraying one's own illness is a way to avoid moral controversy, as the ethics of the artwork are unlikely to be questioned. As the previous research cited in my thesis shows, for almost forty years researchers in different fields have made

463 H Carel, *Phenomenology of illness*, 2016, p. 222, 225.

464 R Adams, author's webpage, accessed Oct, 25, 2016, www.ruthadamsphotography.com/

465 H Carel, 'Phenomenology as a resource for patients' *Journal of medicine and philosophy*, 37: 96–113, 2012, p. 99.

suggestions, claims and moral arguments about how sickness, and suffering in general, should or should not be portrayed in art photography. The biggest controversy circles around showing the actual sufferer or sufferers. As cited in Chapter Two, researchers agree that it is morally acceptable to show suffering and sick people if the message of the image is 'stop this', while others argue that photography can only ever say: 'what a beautiful world'. However, this moral debate has no cause to fire up when the photographic artwork is about one's own illness due to the sensitivity for criticising someone's personal experience, as noted by for example Charlotte Cotton⁴⁶⁶.

There is also another way to steer clear from the endless moral debate; the moral questions are only raised when the images show real, actual people – real suffering. When the circumstances are staged, when the sufferer is staged, the photograph becomes, at least for Sontag, anti-war and anti-suffering. Despite this, 44 artworks from the 67 mapped are documentary, meaning that they show the actual sick people (or parts of them) without deliberately added elements or props. While Henry Peach Robinson thought in the 1800s that it would have been too much to show a real sick person, today it is common. Is sickness so serious or unwanted as a theme that staging it is out of the question, or does the theme only occur to artist when they themselves or their loved ones are sick?

Examining the previous research and considering the ethical issues prompted me towards photographing actual used radiation therapy masks on an anonymous model (*Leftover*) instead of photographing only the mask or adding actual cancer patients into the work, as I wanted to look at the topic without a specific illness experience or ill person.

In addition to the illness works, there are works that approach the theme differently. The anthology *Clinic* (2008) is the biggest individual contributor for looking at the theme of sickness differently. Its nine artworks take sickness and/or disease as their approach. One of them is Stefan Ruiz's *Emergency*, a work that instead of taking 'a doctor's point of view' or 'a patient's point of view' combines them both into a laconic series where everyone is photographed the same way, united by the situation.

Repetition is common in the works depicting disease, for example the works by Dallaporta, Zhaohui and Sundhoff. These works are conceptual, and formally systematic. This repetition can also be a way to create coherence or a category or a class, where the individual photographs make one whole. In addition, repetition can be used as a method to purposefully make the images less effective (less shocking for example) and to integrate them into everyday life. Also, this type of approach can be a way to comment on the historical and contemporary uses of photography as a tool of classification by the authorities. Another reason for this

466 C Cotton, *The photograph as contemporary art*, 2014, p. 141.

concept can be that these artworks lack a combining narrative of an illness experience, and therefore they use other means to create coherence. In a photographic illness narrative, the story, the sickness experience, connects all the images into one story regardless of their style (portraits, details, scenes or archival photographs).

Leftover, my series of leftover medical masks from cancer treatments, was my way to dwell on systematic classification, on the ways in which photography was used in medical categorisation. Furthermore, the work is a testing ground to represent sickness on a general, non-personal level, a way to criticise cultural constructions of cancer, and to look at cancer from afar. It is unifying and autologous as it repeats the same aesthetic in every portrait around the exhibition space. The work aims to underscore the statistical frequency of cancer, how ‘normal’ it is as opposed to abnormal. The sculpture’s title, *Unlimited Number of Cell Divisions*, refers to cancer cells’ biological immortality, to their potential to keep dividing endlessly. The exhibition was an experiment to represent sickness concretely, while simultaneously free of any specific personal illness experiences.

6.2. Life in death

In the previous research cited in Chapter Two, death and mortality are often used to explain the fear of sickness as well as the uneasiness when confronted with representations of the sick. Various scholars have proposed that the photographs depicting sickness, illness and disease disturb us because they remind us of our own mortality and awaken our fear of death, or our fear of our loved ones’ possible deaths (for example O’Neill 2011, Radley 2009, Biernoff 2012).

Nonetheless, there is another way to think; what if it is not death that is terrifying, but life. Aurel Kolnai proposed that death doesn’t disturb us, but life in death; the maggots eating rotten flesh, the life that invades death.⁴⁶⁷ For Kolnai, the state at which something once whole begins to fall apart and dissolute, that is when things get disgusting.⁴⁶⁸ In other words, it is not dying that bothers us but rather that the parts that once constructed a body can transform to something else, or go on living like the HeLa cells. Eugene Thacker suggests that, what haunts us is life and living as they are still unresolved questions.⁴⁶⁹ Perhaps the disturbing part is this unknowing, the arbitrary construction of a border. And this unknowing is what abject forces us to face.

467 A Kolnai, *On disgust*, 2004, p. 53.

468 A Kolnai, *On disgust*, 2004, p. 18.

469 E Thacker, *In the dust of this planet*, 2011, p. 68.

My artwork *White Rabbit Fever* traces sickness to its origins, into the ambiguous, abject borders of life and death in relation to time. I researched the biological and clinical definitions of death. White Rabbit Fever is an effort to contemplate sickness and mortality as a universal part of our existence and to reflect on the often-desired immortal life, but in the form of forever-growing cancer cells. The exhibition presented life in death; maggots are visible in the second image of the decaying rabbit sequence. The work also draws from the concepts of abject and uncanny, illustrating immortality through cancer cell lines.

With White Rabbit Fever, I also set out to see if Korsmeyer’s aesthetic disgust is achievable in practice, to see if disgust can be used as a method to lure the viewer in to dwell with the images and if this dwelling can turn into an aesthetic or mental pleasure. In the exhibition at Gallery Lapinlahti people did dwell and ponder, however it cannot be concluded if it was aesthetic disgust that made them spend time with the images or something else, or even if they found what they saw in any way disgusting. Examining this would require audience response research, which is not a goal of this research.

6.3. The difficult photographs

In this research, I have sought the answer to some photographs’ ability to evoke aversion especially from Kristeva’s and Bataille’s abject, but also from Freud’s uncanny and Menninghaus’ disgust to Misselhorn’s aesthetic disgust. There is no definite answer to be offered, but suggestions. As the works cited in Chapter Five indicate, people learn to be disgusted, and they can unlearn it too; seeing the same photograph again rarely has the same effect as the first time; and also the acceptance that borders are unfixed can change one’s perception. Disgust can turn into fascination, inspiration and discovery. It changes the perceiver more than the thing perceived.

I suggest in Chapter Five that photographs have the ability to be disgusting, uncanny and abject because of their proximity. This proximity essentially stems from photographs’ indexicality, their ability to embody and represent something outside the image as cited in Chapter Five. By proximity I mean nearness in time, space or relationship.

First, photographs can condense time, dramatise it, or freeze what would be otherwise fleeting, and they are seen to have a direct link to specific moments in time. Secondly, photographs are compared and looked at in relation to our physical surroundings. Because photographs offer a fixed, non-negotiable viewpoint and leave the viewer with only two options – to look or not to look – this gives them the ability to transform normal things into uncanny. This is achieved, for example, by showing everyday things from a perspective that looks odd or horrifying, as in Kathryn Parker

Almanas’ photographs in which fabric and fruit are made to look like the aftermath of an autopsy or surgery.

Thirdly, photographs can feel physically linked to our being; people are reluctant to tear up or throw away photographs of loved ones, as cited in Chapter Five. And this mental and physical proximity of photographs is why they can become uncanny and disgusting, as the mere closeness of them threatens to immerse people in it or contaminate them.

However, for a photograph to be abject, it has to be seen in an unsafe context that prevents the viewer from feeling at ease, meaning for example that it is different to look at an image of skin cancer in a medical leaflet compared with in an art gallery. In addition abject is rooted in culture (which also means it can differ from culture to culture); there can be no abject in the first place without borders, classifications or definitions. In other words, something has to be defined as ‘clean’ in order there to be ‘dirty’ and the ‘dirtier than dirty’ – abject – that questions the whole initial definition as discussed in Chapter Five. With regards to this research, seeing a photograph of a human heart outside a human body, for example, can be disturbing.

The concept of abject helps to draw attention to the culturally learned and constructed borders, and especially when combined with disgust research, helps to explain some aspects of why some things, ideas or photographs – depicting diseased body and/or its parts – can disturb.

There are still many things left to explain. For example, the effect of repetition when it comes to photographs of sickness and suffering; they numb, but what is the mechanism and how is it linked to denial and acceptance? As I proposed, photographs’ proximity makes them potent to be abject but what else does this proximity do when it comes to representation?

Defining and classifying is a use of power, as Chapters Two and Three remind us; defining something as illness, or to define someone sick, affects not only individual lives but the whole society. But this defining and categorising is also human nature, according to Mary Douglas, it is a way to make the world understandable, and makes people feel safe; borders bring order to chaos. When these safe borders get tested people might feel very uncomfortable as Chapter Five shows. Defining something as healthy and pure will inevitably produce waste, garbage, and filth – disease. Disease is also Bataille’s waste, the waste that has the power to tear down the very definitions that originally produced it. This questioning of physical or mental borders is also an invitation for a new beginning, to formulate and classify again, to create something new. But maybe this can be done keeping in mind the previous structure or classification. From this perspective, it is not sickness that should be re-defined or questioned but health. Furthermore

photography is inherently intertwined with the construction of borders, as photography is itself a tool for classifying.⁴⁷⁰

In this dissertation I have used Kleinman’s definitions of sickness, illness and disease, which can be seen to emphasise the medical point of view on sickness, the dominant point of view. However, the aim has not been to reinforce how things are but to show how the dominant view is constructed and how it is represented, portrayed, and also challenged in photographic art. My aim has been to open a discussion and give inspiration for thought-provoking works that can challenge the dominant view of thinking and looking at sickness, and open up possibilities for new kinds of representations; for bolder, more critical, more ironic and funnier artworks on sickness (and health).

Having the medical anthropological definitions as a starting point has also had an effect on my artworks. I have collaborated with scientists instead of patients as I have aimed to trace the borders of the definitions, and tried to look into areas where the majority of artists haven’t looked. In addition, photography as a medium is inherently intertwined with science and art through its historical and contemporary use, and the more I collaborated with scientist the more it became evident that both art and science have research and experimentation as their base.

6.4. The dialogue

In artistic research, the artworks and the research do not form a pattern or follow a sequential line but take place simultaneously, testing and commenting on each other. As performance artist and researcher Maiju Loukola defines, artistic research proceeds in an unpredictable way.⁴⁷¹ Thus, as noted before, to make the research reliable, and to position it in relation to other artistic research projects, it is necessary to write out what the required dialogue is with regards to this dissertation.

I have adopted the role of connector; rather than seeing making art and conducting research as separate activities, I am looking where they come together, as at heart they are both rooted in investigation. I can textually examine the writings of disgust, and the artworks can examine the experience through the tactile and corporeal and gut. As noted in the first chapter artistic research starts from the premise that it changes the thing researched, in this way making artworks and making research are not much different; they both create. In addition, as cited in Chapter One,

470 S Sontag, *On photography*. 2011, p. 156.

471 M Loukola, *Vähän väliä (V/ä/h/ä/n v/ä//i/ä): näyttämön mediaalisuus ja kosketuksen arkkitehtuuri*, Aalto University publication series, 2014, p. 21.

artistic research is inherently interdisciplinary and/or transdisciplinary; in other words it connects. When looking back at the four years spent making this dissertation, it has been an active quest of looking for connections and relationships between disciplines, ideas and modes of experiencing; looking at abject in relation to the emotion of disgust, considering fear of death in relation to biological immortality, combining tactile with space, and even physically melting used radiotherapy masks together.

My practice comes close to Finnish artist and scholar Lauri Anttila's working method: for Anttila the camera is a measuring tool. As he sees it, scientific observations concentrate on specific sectors of the world, whereas artistic observations aim for an all-encompassing view by combining intuition and cognition.⁴⁷² Anttila uses scientific methods to create art, and his goal is nothing more than to reunite science and art.⁴⁷³ In my works, for example in *White Rabbit Fever* I set out to document the growth of cancer cells in a scientific, controlled way, but to use the sequences to build a larger view on immortality.

The role of connector can also be seen as a form of dialogue that draws attention to corporeality of connecting that happens not only on an abstract level but also in practice. A connector is not bound to pre-existing roles, and so, instead of acting within the roles of an artist and researcher, a connector can build her or his own role and look from the outside to see where the two positions already overlap (both investigative practices) and also actively create new connections between them. For example, in my research by collaborating with the professor Andersson and creating new ways to experience and think about mutated human cells.

In this research I have connected parts from anthropology, psychoanalysis, psychology, social psychology, sociology, neuroscience, biology and art. For example, Kleinman's definitions were very useful in analysing artworks and they enabled me to see differences that I would not have noticed otherwise. Thus, naturally when using definitions from different disciplines, one has to be careful to understand the terms adequately, as failing to do so can lead to misinterpretations or biases.

In the introduction of this research I quote Teemu Mäki's article in which he writes that becoming conscious of existing theories and practices is like getting a new sense. This sounded too grandiose when I started this research. Now I have to admit that making this dissertation has made me aware and attentive to perspectives and details I was previously unable to see. For example, I was able to notice the visual critique against the stereotypical way of being sick in artworks, detecting conceptual choices in artworks depicting

472 L. Anttila, *Ajatus ja havainto*, Valtion painatuskeskus, Helsinki, Kuvataideakatemia, 1989, p. 103.

473 L. Anttila, *Ajatus ja havainto*, 1989, p.103.

disease, and thinking of immortal life as manifested in cancer cell lines. Making this dissertation has also made me more tolerant and more intrigued about artworks that I had previously deemed uninteresting. The research has also illustrated how much there is still to know.

This research ends with two images. Conducting this research has pushed me toward the endlessly fascinating, biological and philosophical question of life/death and its boundaries. The first image depicts a head of an animal called Hydra after decapitation; a head which will regenerate into a full animal in a course of days. The other image is a portrait titled *One of Them Is a Human #1*, from a series of four portraits, three of which show Japanese human-looking robots (androids) and one that shows possibly a human.

In the ongoing work *Volunteer 4 (Hydra)* I am growing and documenting Hydra, immortal fresh-water polyps, with the aid of professor of biology Robert B. Silver at a laboratory in Syracuse, US. It is a collaboration that combines scientific incentives and art, and also the planned outcome is two-fold, as we aim to make a contribution to scientific research as well as to create artwork that comments on the general practice of science-making and presents a view on immortality.

Hydra do not seem to age at all – making them biologically immortal. However, they can die. During the first week and a half of the project, approximately 30 Hydra died. The majority of them were eaten by microstomum flatworms that had somehow gotten into one of the Hydra culture jars. In addition, two Hydra, which I named Volunteer 4 and Volunteer 7, went missing and remain so.

In addition, Hydra are superstars of regeneration as they can regrow into a full animal from a group of cells. In our first experiments we bisected and trisected green (chlorohydra viridissima) and brown (hydra littoralis) Hydra, and documented their regeneration. The image *Head 2* shows the head part of a trisected brown Hydra. Hydra are also able to clone themselves. They 'bud' their clone from their sides.

Cloning and immortality are also attributes of *One of Them Is a Human*. The portrait shown here was taken at Ishiguro Laboratory, Department of Systems Innovation at Osaka University in Japan. It depicts Erica (Erato Ishiguro Symbiotic Human-Robot Interaction Project), who is an autonomous conversational robot. All the four photographs in the piece are taken so that the robots look as human as possible as I wish to evoke conversation on what it is to be human or alive, and also question what a photographic portrait can or cannot tell from its subject.

The first outcomes of the Hydra collaboration, together with the android portraits, were shown at Gallery Huuto in Helsinki in March 2017, and a video piece at Our Festival in Järvenpää, Finland in July 2017.⁴⁷⁴

474 *Volunteer 4 (Hydra)* at Gallery Huuto in Helsinki, Finland, March 31 – April 16, 2017. *Hydra* (video) was performed with composer and vocalist Maja S.K. Ratkje at Our Festival, Järvenpää, Finland, July 29, 2017.

To conclude, making this dissertation, in addition to gaining a new sense, has expanded the limits of my artist-researcher practice; methods, concepts and collaborations I previously found difficult or complicated, are now possible.



Maija Tammi: *Head 2*. From the series *Volunteer 4 (Hydra)*, 2017 – ongoing.



Maija Tammi: *One of Them Is a Human #1*, 2017. (Erica: Erato Ishiguro Symbiotic Human-Robot Interaction Project.)

7.

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