Not So Soon:
A Photography Project Based on Autoethnographic Research on My Dying Mother

Yoko Lance
BA, BDigitalMedia (Hons)

Queensland College of Arts
Arts, Education and Law
Griffith University

Exegetical dissertation submitted in partial fulfilment of the requirements for the degree of Doctor of Visual Arts

March 2018
Abstract

This research is concerned with the denial of death in society, and it is informed by my position as a Japanese-Australian photographer. The research project *Not So Soon* (2014–2018) consists of a series of photographic and video pieces compiled from photographs and interviews with my terminally ill Mother, Masako Katayama, as well as this exegesis. This research reflects upon my readings of death and dying in direct relation to my Mother, and investigates how a terminally ill mother and her daughter can comprehend the mother’s impending death. In collaboration with my Mother as the principal subject, I consider how the process of dying can be presented to a public who often withdraw from discussion on this topic. Photography can serve, refine, and expand the work of qualitative research; however, only a few have successfully combined research texts with academic rigour and strong visual semiotics rather than utilising photography as a supportive/illustrative tool. The final outcomes of the research contribute to this gap in the field, offering new ways of perceiving death and dying in modern day, multicultural Australia.

Death and dying are considered taboo subjects in many countries, including Australia and Japan. The denial of death in society persists although the stigma has diminished over the years. Contemporary Japanese perspectives of death are similar to those in the West, but some unique attributes can be found in Japanese visual art, such as Mika Ninagawa’s photography book *The Days Were Beautiful* (2017). The metaphysical function of photography has been closely related to death; therefore, I understand photography as an ideal medium through which to portray it. I examine the work of some visual practitioners in the field, such as Mami Sunada, Walter Schels and Beate Lakotta, Sophie Calle, Briony Campbell, Phillip Toledano and William Yang, to support the numerous ways in which photographers have approached the topic of death.

Employing an insider approach, portraits and video interviews explore my Mother’s position as a terminally ill patient. In 2014, my Mother was diagnosed with stage 4 ovarian cancer. She had her ovaries removed and started chemotherapy soon after. A few months after the surgery, I began to focus on my Mother’s perception of death and dying, utilising questions from two fear-of-death scales. These death scales were read in conjunction with studies on death and dying, in order to highlight how these discourses might be translated into creative practices that seek to understand the
profound and difficult task of facing death. These perspectives influenced the exchange between my Mother and me, and are seen in the video piece entitled *Not So Soon* (2015). Through my research, I learnt that my Mother accepts her fate, but still harbours great fear of the possible pain and suffering she may experience as her illness progresses. The outcomes are presented through photography and video images as extended forms of still photography.

Throughout the course of this doctoral research, I conducted a diary exchange project with my Mother, and some extracts of these entries were displayed in both English and Japanese alongside photographic works in a solo exhibition held in Sydney. The process of assembling works for the exhibition clarified what I truly wanted to express through the project: that receiving a cancer sentence is cruel, but my Mother and I have been granted one last chance to cherish our remaining time together. In this exegesis, I analyse our previous mother–daughter relationship as well as how it has changed in recent years.

Drawing on the field of autoethnography, I developed a visual methodology using still and moving images to foreground ways in which my Mother and I can comprehend and express our relationship to one another, as well as to death and dying. At the same time, the practical outcomes of this research aim to expand empathic modes of understanding death in those who will inevitably come to know its impact upon their lives.
Statement of Originality

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

Yoko Lance 12/2/2018
Signed Dated
Ethics requirement

This research documenting my terminally ill mother, and any people appearing in the same frame as her, through photography, videos, and textual information has been approved by the Griffith University Human Research Ethics Committee, GU Ref: 2016/608.
# Table of Contents

Abstract ................................................................................................................................. 2  
Statement of Originality .................................................................................................... 4  
Ethics requirement ............................................................................................................. 5  
List of Figures ..................................................................................................................... 8  
List of plates ....................................................................................................................... 9  
Acknowledgements .......................................................................................................... 10  
Preface ............................................................................................................................... 12  
Introduction ....................................................................................................................... 14  
Chapter 1: Death in Context ............................................................................................ 16  
  1.1 Denial of Death in Society ...................................................................................... 16  
  1.2 Life and Death in Japan as Seen in Mika Ninagawa’s *The Days Were Beautiful* ...................................................................................................................... 24  
    The Colour Red in Japan .......................................................................................... 25  
    Japan’s Faith-Based Approach to Death and Dying ............................................ 30  
    Cherry Blossoms as a Motif of Life and Death .................................................. 32  
Chapter 2: Methodology ................................................................................................ 35  
  2.1 The Metaphysical Function of Photography and Its Relation to Death .......... 35  
  2.2 Photography and Autoethnography .................................................................. 36  
  2.3 Kübler-Ross’s Ethnographic ‘Storytelling’ Approach ....................................... 39  
  2.4 An Analysis of Visual Practitioners’ Inquiries into Death and Dying .......... 40  
    2.4.1 Visual Practitioners in Various Creative Fields .......................................... 41  
    2.4.2 Visual Practitioners in Documentary Photography Practice .................. 44  
Chapter 3: *Not So Soon* ............................................................................................... 51  
  3.1 Fear of Death and Video Interviews with My Mother .................................. 52  
    Fear of Death ......................................................................................................... 52  
    Fear-of-Death Scales ............................................................................................. 53  
    My Mother Masako’s Perception of Death and Dying ...................................... 55  
    *Not So Soon* Video ............................................................................................ 58  
  3.2 Diary Exchange Project and *Not So Soon*, at Head On Photo Festival, Sydney ................................................................. 62  
  3.3 Our Mother–Daughter Relationship amid the Fear of Death .................... 70  
    Oedipus Complex and My Separation from My Mother ................................... 71
3.4 Between Two Cultures: Group Exhibition *Erehwon* ..................................... 85

Conclusion.............................................................................................................................. 88

Appendix 1: Ethics information................................................................................................ 93

Appendix 2: The Reasons for Death Fear Scale................................................................ 98

Appendix 3: The Collet-Lester Fear of Death Scale Version 3.0.......................... 99

Appendix 4: Questionnaires for interviewing my Mother ........................................ 100

Appendix 5: Interview with Masako: whole original transcript in Japanese
..................................................................................................................................................103

Appendix 6: Not So Soon final video transcripts and translations for subtitles
..................................................................................................................................................115

Appendix 7: Diary Exchange Project Texts.................................................................121

Appendix 8: List of Research Outputs/Activities ...................................................129

Reference List .....................................................................................................................136

Reference List of images .................................................................................................141

Bibliography........................................................................................................................142
List of Figures

Figure 1. Pier Francesco Cittadini A Vanitas Still Life with Violin c1681, oil on canvas 101 x 164 cm.......................................................... 17
Figure 2. Yoko Lance Garbage Bin after the Cremation (from the ‘For Grief’ series) 2013 .......................................................................................................................... 18
Figure 3. Yoko Lance Real Burial After a Solemn Ritual without Attendants (from the ‘For Grief’ series) 2013 .......................................................... 18
Figure 4. Yoko Lance Cremator (from the ‘For Grief’ series) 2013 .......................................................... 18
Figure 5. Yoko Lance Ashes (from the ‘For Grief’ series) 2013 .......................................................................................................................... 19
Figure 6. Yoko Lance Masked Man (from the ‘For Grief’ series) 2013 .......................................................................................................................... 19
Figure 7. Yoko Lance Magnetic Stick to Remove Metal Substances from Ashes (from the ‘For Grief’ series) 2013 .......................................................................................................................... 19
Figure 8. Yoko Lance Grinder for Remains after the Cremation (from the ‘For Grief’ series) 2013 .......................................................................................................................... 20
Figure 9. Yoko Lance Kim Rodda Preparing for a Funeral (from the ‘For Grief’ series) 2013 .......................................................................................................................... 23
Figure 10. Yoko Lance Donna Rostron Reaching to a Coffin (from the ‘For Grief’ series) 2013 .......................................................................................................................... 23
Figure 11. Yoko Lance Tim Connolly Operating the Cremator (from the ‘For Grief’ series) 2013 .......................................................................................................................... 23
Figure 12. Donna Gibson Release 2010 from National Portrait Prize exhibition 2011 .......................................................................................................................... 24
Figure 13. Mika Ninagawa Dust cover of The Days Were Beautiful [Utsukushii Hibi] 2017 .......................................................................................................................... 25
Figure 14. Torii gate example: 663highland Yasuhideinari-sha in Kamikawa Hyogo prefecture Japan 2011 .......................................................................................................................... 27
Figure 15. Koichi Sato No Title 2016, Mika Ninagawa (right) holding her father Yukio Ninagawa’s portrait with her mother (left) at the funeral .......................................................................................................................... 28
Figure 16. Mika Ninagawa (from The Days Were Beautiful) 2013 .......................................................................................................................... 29
Figure 17. Mika Ninagawa (from The Days Were Beautiful) 2017 .......................................................................................................................... 33
Figure 18. Mika Ninagawa (from The Days Were Beautiful) 2017 .......................................................................................................................... 33
Figure 19. Mami Sunada Ending Note poster 2011 .......................................................................................................................... 42
Figure 20. Walter Schels and Beate Lakotta The Life Before Death 2008 .......................................................................................................................... 43
Figure 21. Sophie Calle Rachel Monique 2010 .......................................................................................................................... 44
Figure 22. Briony Campbell The Dad Project 2009 .......................................................................................................................... 45
Figure 23. Phillip Toledano Days with My Father 2006 .......................................................................................................................... 47
Figure 24. William Yang Allan (from the series of Sadness) 1990 .......................................................................................................................... 48
Figure 25. Yoko Lance Captain Eddy 2012 .......................................................................................................................... 57
Figure 26. Yoko Lance transcript 2015, categorising the transcript with five colours .......................................................................................................................... 58
Figure 27. Donal Fitzpatrick et al. Erehwon Online Exhibition Catalogue 2017 .......................................................................................................................... 87
List of plates

Plate 1. Yoko Lance After the surgery (from the ‘Not So Soon’ series) 2015 ............... 55
Plate 2. Yoko Lance Not So Soon (video) 2015, 6:58 min ................................................... 59
Plate 3. Yoko Lance Losing hair (from the ‘Not So Soon’ series) 2015 ...................... 60
Plate 4. Yoko Lance Still smoking (from the ‘Not So Soon’ series) 2015 ....................... 60
Plate 5. Yoko Lance Resilience (from the series ‘Not So Soon’) 2015 .......................... 61
Plate 6. Yoko Lance Not So Soon Sydney exhibition 2016 ........................................... 63
Plate 7. Yoko Lance Not So Soon Sydney exhibition – wall 2016 .............................. 63
Plate 8. Yoko Lance Not So Soon Sydney exhibition – text 01 2016 .......................... 64
Plate 9. Yoko Lance Not So Soon Sydney exhibition – text 05a 2016 ......................... 64
Plate 10. Yoko Lance Not So Soon Sydney exhibition – text 05b 2016 ........................ 65
Plate 11. Yoko Lance Not So Soon Sydney exhibition – text 06 2016 ........................... 66
Plate 12. Yoko Lance Not So Soon Sydney exhibition – text 07 2016 ............................ 67
Plate 13. Yoko Lance Not So Soon Sydney exhibition – text 08 2016 ......................... 68
Plate 14. Yoko Lance Not So Soon Sydney exhibition – text 10ab 2016 ...................... 69
Plate 15. Yoko Lance Not So Soon Sydney exhibition – text 10cd 2016 ....................... 69
Plate 17. Yoko Lance Legs of mother and daughter (from the ‘Not So Soon’ series) 2016 ......................................................................................................................... 75
Plate 18. Yoko Lance Mammogram (from the ‘Not So Soon’ series) 2014 .................. 76
Plate 19. Yoko Lance Mother and daughter waiting for the doctor’s appointment (from the ‘Not So Soon’ series) 2016 ......................................................................................................................... 79
Plate 20. Yoko Lance Mother (22) and daughter (3 months) (from the ‘Not So Soon’ series) 2014–2017 ......................................................................................................................... 80
Plate 21. Yoko Lance Bye for now (from the ‘Not So Soon’ series) 2016 ....................... 81
Plate 22. Yoko Lance Japanese lunch together at Helensvale (from the ‘Not So Soon’ series) 2016 ......................................................................................................................... 82
Plate 23. Yoko Lance Japanese lunch together at Southport (from the ‘Not So Soon’ series) 2016 ......................................................................................................................... 83
Plate 24. Yoko Lance Happy Birthday, Mum (from the ‘Not So Soon’ series) 2016 ...... 83
Plate 25. Yoko Lance Cuddles (from the ‘Not So Soon’ series) 2016 ............................. 84
Plate 26. Yoko Lance Jacarandas (from the ‘Not So Soon’ series) 2017 ....................... 84
Plates 27. Yoko Lance Erehwon 01 2016 ........................................................................... 86
Plates 28. Yoko Lance Erehwon 02 2016 ........................................................................... 87
Acknowledgements

This project and research could not have been accomplished without the unwavering support of many people.

I would like to express my deepest gratitude and appreciation to my principal supervisor, Dr Laini Burton, for her continuous guidance and advice as well as her touching assurance during these past four years and my Honours year. I honestly could not have presented my thesis without your critical reviews and warm support.

I would like to extend my sincerest appreciation to my associate supervisor, Dr Heather Faulkner, who has been a profound influence since I started studying photography academically. You taught me the joy of photography with critical analysis right from undergraduate level and I thank you for being a rare academic in the field and a role model. Your knowledge and understanding of Japanese culture also opened many doors to engage my thoughts and ideas.

I would also like to express my very great appreciation to another associate supervisor, Dr Margaret Gibson, for guiding me in the sociological study of death as well as for her gracious support in visual arts.

My heartfelt thanks also go to Assoc. Prof. Donal Fitzpatrick for being my principal supervisor for the first year of my doctoral research. It was an honour to have regular discussions with you to expand the foundation of this research. The issues in society and philosophical questioning related to the topic of death and dying that we discussed became the backbone of this thesis. Thank you for kindly supporting our group exhibition and being a curator, leading us to the next level.

I would like to offer my special thanks to Dr Debra Bath for your kind support and guidance regarding study in psychology, especially in the area of fear of death.

I wish to thank my editor and translator, Naomi Roulston, for supporting me throughout this project. I am very grateful to have a person like you who could both edit my English texts and translate various Japanese texts for different occasions ranging from artistic statements to academic writing. I also thank my editors Eva Rosenorn and Adee Macdowell for their kind support and professionalism.
My husband John and daughters Midori, Mika, and Mia deserve special thanks for their very patient support throughout my study. I could not have gone down this challenging path without you.

Finally, I especially thank my mother, Masako Katayama, for letting me conduct this research about her and for opening herself up. I could not possibly have taken any other photos with such intimacy, sometimes to the point of intrusion. I deeply appreciate your patience, wholehearted understanding, and unconditional love. I love you dearly, Mum.
Preface

On a cold winter morning in 2014, I received a phone call from my Mother, who told me that she had been diagnosed with stage 4 ovarian cancer. It was just over six years since she had had a mastectomy for her very early stage of breast cancer. I Googled 'stage 4 ovarian cancer survival rate' straight away, and the results showed that there was only a 10 percent five-year cure/remission rate.

My Mother decided to undergo chemotherapy after the doctor told her that she would not live a year without it. However, one afternoon, I found out that she was still smoking. I cannot explain how furious I was at the time. "Taking chemotherapy and still smoking? Do you want to live or kill yourself? Why would you suffer this much to go through chemotherapy if you want to die? Don't you know how serious this situation is now? You only have a 10 percent chance of living five years!" She made some silly excuses. A few days later, I found out my Mother was still smoking.

After a few months of chemotherapy, Mother became really weak and frail. Her skin colour became dark, her nails became black, and she lost most of her hair, including her eyebrows and eye lashes. She had pins and needles in her hands and feet all the time, and could not even walk on the tiled floor as it caused pain. She started using a walker to perform some easy household duties and for going out. She could not even sit up and tinker on play with her laptop anymore like she used to. All she could do was hold an iPhone and play games. “It’s good to play games all day. That way I do not have to think about anything. I would start crying otherwise,” she would say.

Suddenly, I realised what a horrible experience she is going through, and how hard her life is. I thought I knew, but I did not really understand Mother’s situation until she had become this weak. It must be tremendously hard for my Mother to face reality, which is probably why she tries to avoid facing it by smoking and playing games all day. It is easy to say that my Mother is silly. But this is the way she tries to ‘live’. In my Honours project “For Grief” (Lance 2013a; Lance 2013b), I emphasised the significance of talking openly about death and dying, but I have realised how hard this is in reality and it explains why we attempt to look away from the fact of death. Our ignorance and denial of death is sometimes an effective safety blanket to overcome our fear of death. I also realised that I tend to project my own fear and denial of death upon my Mother.
This research project *Not So Soon* (2014–2018) encompasses my journey to try to cope with this emotionally challenging time and to gain a greater understanding of my Mother, and our relationship, through the camera lens.
Introduction

Death and funerals are considered taboo subjects in many countries including Australia and Japan. People often avoid talking about death and dying, and the words ‘death’ and ‘dead’ are often rephrased as ‘loss’, ‘gone’, or ‘passed away’, and the words ‘deceased’ or ‘remains’ are used instead of ‘dead body’ and ‘corpse’. Many people fear death consciously or unconsciously and deny our fate, since it is not easy to accept our own death. This research aims to contribute to existing discourses on death and dying and to provide an opportunity for people to consider their own mortality and approaches to death. The research outcomes comprise video and photographic artworks and this exegesis, which are all based on an autoethnographic methodology.

As a Japanese migrant who has lived in Australia for almost twenty years, I sometimes feel that I do not belong to any particular culture. However, multiculturalism is a part of Australian culture. I believe my Japanese migrant perspective on issues around death and dying in an Australian context can contribute to the broader attitudes towards these issues in our society.

This research investigates how a terminally ill mother and her daughter comprehend the mother’s impending death, and how the mother–daughter relationship, amidst the process of dying, can be presented to a public who often withdraw from discussion of the topic.

When speaking Japanese, I normally call my Mother ‘Okasan’ casually or ‘Haha’ in formal situations; when speaking English, I call her ‘Mum’ or ‘Mother’. For consistency, I refer to her as ‘Mother’ in this exegesis.

I undertook a range of strategies to complete this research. Employing an insider approach, I investigated my Mother’s position as a terminally ill patient diagnosed with stage 4 ovarian cancer through photographic portraits and video interviews.

Photography can serve, refine, and expand the work of qualitative research; however, only a few artists have successfully combined research texts with academic rigour and strong visual semiotics rather than utilising photography as a supportive/illustrative tool. With a university education in photography and communication, and experience
in the media industry as a writer and photographer, I argue that the final outcomes of this research titled *Not So Soon* contribute to new ways of perceiving death and dying in modern-day, multicultural Australia.

Chapter 1 discusses the denial of death in society and perceptions of death in Japanese culture to provide a context for this research. The denial of death in society persists, although the stigma of death has diminished over the years. Contemporary Japanese perspectives of death are similar to those in the West, but some unique attributes can be seen in Japanese visual art, such as Mika Ninagawa’s photography book *The Days Were Beautiful* (2017), which I will review in this context.

Chapter 2 considers the metaphysical function of photography on death and explains my methodology. To investigate responses in society related to death and dying, I examine works by the following visual practitioners: Mami Sunada, Walter Schels and Beate Lakotta, Sophie Calle, Briony Campbell, Phillip Toledano and William Yang. These practitioners have been selected because they individually articulate responses to death that reflect my own aims; that is, to comprehend the impact and gravity of mortality and death in our lives and the way this can be explored through creative practices.

Finally, Chapter 3 describes the project *Not So Soon*, which focuses on my Mother as a terminally ill patient, and details how it is presented through visual work. The results are recorded in four separate bodies of work: a video piece entitled *Not So Soon* composed of video interviews with my Mother and photographs I have taken; a solo exhibition held in Sydney in 2016, featuring a diary exchange project between my Mother and me; photographs and text analysis of our mother–daughter relationship in the past as well as how it has changed with the fear of impending death; and a group exhibition titled *Erewhon* held in Brisbane in 2017.
Chapter 1: Death in Context

In this chapter, I contextualise this research on the denial of death in society, and Japanese perspectives of life and death. I expand this analysis to include a discussion on the photography of Mika Ninagawa; in particular, her photobook *The Days Were Beautiful* (2017).

In most societies, including those in Japan and Australia, death and funerals are often considered as taboo subjects that people avoid talking about. However, death was not traditionally suppressed or denied. Philippe Ariés (1977) explains in his book *The Hour of Our Death* that before the advent of modern state systems of management and science-based medicine (key factors of modernity), death used to be a more frequent event as people died from disease more often. Indeed, random violence, disease and the loss of life from natural disasters were less able to be controlled. People were therefore familiar with the fact of death, and were less sensitive about it (1977). As Ariés states, death was once seen as “tame”, which he explains as “the ancient attitude in which death is close and familiar yet diminished and desensitised” (1977, 28), and also a social event for the whole community. However, Ernest Becker claims in his book *Denial of Death*, “that of all things that move man, one of the principal ones is his terror of death” (1973, 11). This fear of death leads to the denial of death in many contemporary societies and exists in the following contexts.

1.1 Denial of Death in Society

Becker (1973) and Geoffrey Gorer (1955) argue that the influence of religious beliefs is less prominent in contemporary society, and the belief in life after death does not relieve the fear of death enough anymore. The rise of individualism in the twentieth century has also contributed to how rituals and ideas associated with death have become separated from the community.

Historically, people died at home and family members cleaned the body and dug a hole for the grave. Norbert Elias (2001) points out that a healthier environment and medical improvements have contributed to people living longer; therefore, the idea of death has become more distant from everyday life for many. Ariés (1977) also explains that
death is now managed by medical institutions and funeral homes, and the duty of family members has become less of a burden. These shifts in society have made dealing with death a relatively uncommon event.

On the other hand, Allan Kellehear states, "death motivates and activates people like little else because historically biological death has been viewed as no death at all, but rather, the most complicated and challenging part of living" (2007, 47). Throughout art history, the subject of death has motivated many artists to create work, including vanitas or memento mori.

Figure 1. Pier Francesco Cittadini A Vanitas Still Life with Violin c1681, oil on canvas 101 x 164 cm

The subject has not lost its appeal for contemporary artists, who continue to explore its relationship to human existence. In the following chapter, contemporary works by Mami Sunada, Walter Schels and Beate Lakotta, Sophie Calle, Briony Campbell, Phillip Toledano and William Yang are analysed to establish how artists approach the topic of death and dying today.

In previous research undertaken for my Honours project “For Grief”, I discovered that people both face and deny death (Lance 2013a; Lance 2013b). For this project, I conducted a series of social documentary photographic surveys and video interviews with three funeral directors in Southeast Queensland. During this field research, I witnessed and captured some unfamiliar images as evidence of the denial of death and the behind-the-scenes activities of funeral homes. Some facts of funeral and burial processes are hidden from the public eye, and impressions of death and funerals are carefully sanitised in our society.
Figure 2. Yoko Lance *Garbage Bin after the Cremation* (from the ‘For Grief’ series) 2013

Figure 3. Yoko Lance *Real Burial After a Solemn Ritual without Attendants* (from the ‘For Grief’ series) 2013

Figure 4. Yoko Lance *Cremator* (from the ‘For Grief’ series) 2013
Figure 5. Yoko Lance *Ashes* (from the ‘For Grief’ series) 2013

Figure 6. Yoko Lance *Masked Man* (from the ‘For Grief’ series) 2013

Figure 7. Yoko Lance *Magnetic Stick to Remove Metal Substances from Ashes* (from the ‘For Grief’ series) 2013
One of the photographs was of a garbage bin at a crematorium (Figure 1). I was shocked to see some material which used to be a part of someone’s body displaced and discarded. Logically, those metal parts cannot be a part of our ashes and it makes sense that this waste is disposed of in the bin. However, I felt extremely uncomfortable seeing this. It reminded me of the remains of Auschwitz victims during the Nazi era. The idea that all of us face the same demise made me feel uneasy.

Another day, I attended a funeral and burial ceremony with the permission of the funeral attendants. When it finished, I captured a few shots and started to wander around to take more images of the cemetery. After all the attendants left, a few men and a bobcat approached the burial site, and started working there (Figure 2). There was no sad, dramatised music or solemn rituals. This was the ‘real burial’ after all the ceremonies were conducted in a calm beautiful manner. Again, it is logical to think about using heavy machinery to bury a body. However, I was shocked to witness this as I had never seen this before, and I realised how much of the ‘real’ facts of burial are carefully sanitised.

I also captured the storage room at one of the funeral homes (Figure 3). Among all the regular paper work in the storage room were containers of ashes, stacked very neatly. I felt awkward seeing the ordinary objects used in everyday businesses sitting together with these containers bearing the ashes of people. The containers were labelled with the names and addresses of the deceased. One container had a hand-written note that said ‘not paid’. The process of cremation is not widely known either. In one image, I
have photographed the cremator, with the front door open in order for a viewer to observe inside (Figure 4). This door is normally shut during the process. These days, cremators are controlled by computers, with temperature, oxygen levels, and length of cremation all well managed. After the cremation process is complete, the remains are swept into a metal container. When we think about ‘ashes’, we often imagine a powdery substance; however, the remains of a human body normally contain many chunks of bones (Figure 5). When the temperature of the remains is cooled down, they are taken away with metal objects, and then the bones are ground down. The tools and the actual procedure vary depending on the crematorium.

Another image shows a man wearing a mask to avoid inhaling the powdery substance (Figure 6). Behind him is one of the cremators used in this facility. All the metal remains, such as coffin nails or artificial limbs, are separated with a magnetic stick (Figure 7), and large items are separated using a sieve. Figure 8 shows a grinder used in a particular facility; the drum of this machine turns like a washing machine and there are three metal balls inside.

If the images above can serve as evidence of the denial of death in society, how can we explain that we frequently see images of the dead often in mass media, such as movies and TV news, in our contemporary society?

Some scholars, such as Tony Walter (1991) and Atushi Sawai (2005), state that death is both denied and accepted. We see death in the mass media frequently, such as news of natural disasters, death of celebrities, dead people in crimes, and hospital dramas. Sawai explains two diverse types of death appearing in mass media. One is ‘death as information’ and the other is ‘death as pornography’ (Sawai 2005). Death as information can be seen in fictional productions, such as novels, movies, or TV dramas, and these narratives are often consumed as guideline information on life and death. For example, the hospital drama ER (1994-2009) informed audiences how death appears in medical institutions, and the crime investigation drama Bones (2005-2017) depicted death from a scientific perspective. Non-fictional programs such as news and documentaries also provide information of death. News of death tolls of natural disasters, wars, and victims of crimes are reported in newspapers every day, and deaths of celebrities are often displayed on the front page of some gossip magazines. Many documentaries follow cancer patients and capture the vulnerabilities of human
beings, and how we seek some hope in these tragic situations. These inform us how we should face death and accept it.

In 1955, Geoffrey Gorer originally introduced the argument of ‘death as pornography’ in his article “The Pornography of Death” and Sawai Extended on this. In the Victorian era, death was a subject that people talked openly about, while the topics of birth and sex were considered taboo. Now death is suppressed as taboo in many developed countries, and birth and sex are subjects openly discussed in public. Sex is still considered as a taboo subject sometimes; however, it is even a part of child education at school. We can see this 'death as pornography'—the pleasure of consuming suppressed taboos—in some forms of contemporary entertainment, particularly films and video games.

The funeral directors I interviewed for my research for “For Grief” (2013a) concurred that their stigmatisation has been eased over the years because of the contemporary exposure of death in society. Although they had all experienced some level of stigmatising in the past, their testimonies revealed that they feel the acceptance of death in society has increased over the last decade. One of the participants mentioned:

When I started in the funeral industry [fifteen years ago, in] the church I attended at the time, I conducted a couple of funerals for families within the church. And after I did the services, I almost felt like I am[was] alienated . . . I think it’s changed over the years . . . it’s now getting to the stage where I will go out with my friends and sit down and have a meal, and sometime of the night, we will talk about death, dying and funerals. It’s becoming more open, and I think it’s good for the industry as well as people on the whole. (Lance 2013b)
In her text *Photography and Mortality: An Australian Case Study*, Helen Ennis (2013) also points out that end-of-life and post-mortem portraits have started to appear more frequently in photography competitions in Australia, including the National Photographic Portrait Prize, Head-On Photographic Portrait Prize, and Olive Cotton Award for Photographic Portraiture. Ennis contributed to the discourse on the issue of death and dying through her exhibition *Reveries: Photography and Mortality* at the National Portrait Gallery in 2007 as well as her book of the same title (Ennis 2007). Ennis believes that in the years following her exhibition it has become more widely accepted to present images of death in the public domain. In 2007, Ennis was required to use a warning sign and to carefully consider texts and a spatial layout to avoid
confronting the audience when installing her exhibition. However, by the time the National Photographic Portrait Prize was held in 2011 in the same gallery space, this practice of displaying images related to death was no longer required. Ennis explains this phenomenon with a range of examples, such as *Release* by Donna Gibson (2010).

In contemporary Australian society, death and dying are both denied and accepted. The denial of death is diminishing gradually, but some facts of death are still carefully sanitised. *Not So Soon* is created in this context. Its aim is to encourage discussion about the reality of death, how we might face it and how we face the death of those we love.

1.2 Life and Death in Japan as Seen in Mika Ninagawa’s *The Days Were Beautiful*

My Mother and I still share some core Japanese perspectives we value as migrants from Japan even though we have lived in Australia for such an extended period. Contemporary Japanese perspectives of death are similar to the West, but some unique attributes can be observed. To discuss perspectives of death and dying in Japan, I will analyse *The Days Were Beautiful* (2017), a recent work by one of the country’s most renowned photographers, Mika Ninagawa. Although Ninagawa’s work...

---

1 Other examples that Ennis (2013) listed are as follows: Anton Perry *Autumn Reverie* (2012), Cal MacKinnon *Fay sleeping – Fiona (daughter) and Rodney (son) bedside, Wongaburra Nursing Home* (2013) from the Olive Cotton Award 2013; Gil Meydan *Noah* (undated) from the Head-On Photography Portrait Prize in 2011; Sommer Atkinson *Gone to heaven* (2011) from the National Photographic Portrait Prize 2011; and Katerina Mantelos *Athina, 98 years of life* (undated) from the Head-On Photographic Portrait Prize in 2009.
is not a typical representation of traditional Japanese culture, her unique artistic pursuit can be translated as a contemporary expression of Japanese cultural reflection.

**The Colour Red in Japan**

Ninagawa came to prominence in Japan in the 1990s during the rise of young female photographers and their ‘girly photos’ [onnanoko shashin] that centred on self-portraits. These photographs were often taken by compact cameras embracing ‘cute’ [kawaii] things or the photographer herself as an immature female figure. Ninagawa won top awards in the *Shashin-Hitotsubo-Ten* [3.3m² Photography Exhibition Awards] and the *Canon Shashin-Shinseiki* [Canon New Cosmos of Photography] in 1996. Ninagawa gradually moved away from self-portraits and daily life events, earning high acclaim for her portrait photographs for fashion pages and musicians and becoming sought after by many celebrities for their photobooks. Meanwhile, she also gained wide popularity, primarily among young females, for her close-up photographs of flowers, cherry blossoms, and goldfish. *The Days Were Beautiful* (Ninagawa 2017)² is a collection of Ninagawa’s photographs taken around the time of the death of her father, distinguished stage director Yukio Ninagawa.

![Image removed due to copyright restrictions]

*Figure 13. Mika Ninagawa Dust cover of The Days Were Beautiful [Utsukushii Hibi] 2017*

In Japan, as in the West, black is usually the colour that symbolises death. White is also traditionally emblematic of death and funerals in Japan, as exemplified by white attire for the dead and white chrysanthemums used to decorate the altar at funerals.

² The original Japanese title is *Utsukushii Hibi*. 

However, what first strikes a reader upon opening Ninagawa’s book is the overwhelming use of the colour red. Under the dust jacket, printed with flowers in light hues, is the vivid red of the hardcover. The colour red has particular meanings in Japan, although such vibrant colours are also characteristic of most of Ninagawa’s photographs, and many of her works effectively incorporate the colour red.

For example, a striking red has also been used on the cover images of some of Ninagawa’s other published works including, *like a peach* (2002), *Acid Bloom* (2003) and *mika* (2004). Likewise, red walls have provided the backdrop for the works in her solo exhibitions including *Scenes of Mild Poison* [*Maroyaka na Doku Geshiki*] at the Parco Gallery in 2001 and *mika over the rainbow* at the Laforet Museum Harajuku in 2001 and 2004 respectively. Red could thus be said to be one of Ninagawa’s signature colours. The photographer’s office, ‘Lucky Star’, has what Ninagawa calls the “red room”—a room with a red floor and walls. In one interview, she notes, “This is where my ideas come together. I also have drinks here on the odd occasion with friends” (Anazawa 2009, 168). She also mentions in another interview that red is her favourite colour, explaining she does not intentionally choose vivid colours to create her images but that she is naturally attracted to them (1050+ Toyo Ink 2013).

In Western culture, red is commonly used to attract attention, to signal caution and danger, and to flag mistakes and failure; red lights, stop signs, and red pen corrections are some such examples. The effectiveness of red as a colour to enhance appeal, sex, romance, and desire has also been studied in the field of psychology (Mehta and Zhu 2009; Buechner et al. 2014). Ninagawa’s works often utilise the psychological effect of dramatic shades of red. While red is used in modern-day Japan in many situations similar to the West, it also possesses a meaning that is unique to Japan. The red sun on the national flag has its foundations in rice farming. Shinmei shrines of Shinto throughout Japan that worship the sun goddess Amaterasu Omikami, including the grand shrine Ise Jingu, are a testament to the strong relationship between Japanese culture and the sun. A diplomatic message was sent from the King of Yamato (Wa) of

---

Japan to Emperor Yang (Yodai) of the Sui Dynasty in China in 607 as follows: “The emperor of the Land of the Rising Sun is writing to the emperor of the Land of the Setting Sun, and I hope you are doing well [日出處天子致書日沒處天子無恙云云].” (Zheng 636). This validates that part of the Japanese identity is deeply rooted in the fact that the Japanese Archipelago at the eastern extremity of the Eurasian continent is where the sun first rises on the vast landmass that unites Europe and Asia. The word ‘Japan’ is used in English; however, the actual name of the country in Japanese is Nihon or Nippon [日本], meaning ‘the land of rising sun’. Furthermore, red and white are often used for celebrations in Japan, with red symbolising good luck when paired with white. Red is also used to avert evil and protect from misfortune; thus, shrine torii gates are red, the Japanese imperial princess wears a red kimono (called an ojiaka, meaning ‘red’) when she turns three, and senior members of society celebrate longevity by wearing red sleeveless kimono jackets (called chan-chan-ko) when they turn sixty.

That Ninagawa used red in her photobook on the theme of the death of her beloved father suggests not only that it is one of her signature colours, but also because it may communicate her feelings of respect for the departed and signal a celebration of his

---

4 In Japanese, ‘日’ means sun and ‘本’ means where it begins.
Further, at Yukio Ninagawa’s funeral on 16 May 2016, Ninagawa was shown in newspapers and television news programs cradling a portrait she had taken of her late father (NihonTV 2016; Sankei-Shimbun 2016; Daily-Sports 2016). In the portrait, her father is standing under a red moon on the stage of his masterpiece *NINAGAWA Macbeth*.

The majority of Ninagawa’s original works centre on the theme of fleeting beauty. Art critic Midori Matsui reviews that Ninagawa’s photographs depicting flowers, particularly cherry blossoms, and pretty young girls “sense the impermanence of life through the transience of individual beauty and thus seek to anchor the eternal beauty with art” (Matsui 2009). However, Motoaki Hori of the Tokyo Opera City Art Gallery points out that,

> Although the photos are somewhat emotional, there is not an iota of tragic heroism. Just as an ancient poet chanted, ‘Cherry blossoms are all the more beautiful because they fall. Nothing is eternal in the world we live in’ (*Tales of Ise*, poem 82)\(^5\), they have a strength that could be said to be positive. (Hori 2009, 190)

While Ninagawa is fascinated with beauty because of its finite existence, what is important for her is not sorrow or negativity towards that which fades away, but rather the ‘beauty’ of that very moment. In an interview about her *The Days Were*  

\(^5\) Original poem in *Isemonogatari* [*Tales of Ise*], poem 82 (Anonymous c900) in Japanese: *Chirebakoso Itodo Sakurawa Medetakere Ukiyoni Nanika Hisashikarubeki*. 
Beautiful photographic exhibition at the Hara Museum in May 2017, Ninagawa said the photograph of her father’s swollen, jaundiced hand was the only one included for showing his struggle, saying, “I hesitated right up to the last minute because it’s easy to get sentimental, but putting it in made it easier to convey [the situation]” (eiga.com 2017). She did not think that this series of work that depicts dying so directly, portraying sadness so readily, needed such sentimentality.

Her photographs focusing only on the beauty of life in that moment are not a form of escapism. As Hori pointed out, the common theme throughout Ninagawa’s works is not escape, but a sense of affirmation towards the world that envelopes Ninagawa and her subject.

In an interview with Miho Kawaguchi, Ninagawa made a profoundly interesting remark. She relayed that when she was about ten years old, she was preoccupied with what happens when we die, and at the time lapsed into a long despondent silence. Her father attested that it continued for several months. He spoke with her homeroom teacher about it after school and she eventually started to brighten up, but Ninagawa says of that time:

What I was thinking about at the time was that I did not want my dear father and mother to die before me. I know that that is seemingly unnatural and I know that there is nothing I can do about it. So I think agonising over that lost out to the fun things in reality. When I analyse it now, it’s okay to mope about something if moping will change things, but there’s nothing you can do about
that sort of thing, is there? So I think I just got sick and tired of worrying.
(Kawaguchi 2009, 62)

Thinking about death and then accepting the reality of it from a young age has led to Mika Ninagawa becoming a photographer known for recognising the fleeting beauty of now, and her ability to express a desire to sublimate it more than anyone else. Ninagawa gradually developed her idea of the topic of death and created *Everlasting Flowers* (Ninagawa 2006), capturing ‘not living’ flowers inspired by the artificial flowers in cemeteries (Kawaguchi 2009), and later *Noir* (2010), capturing life and death with images including animals in pet shops, chunks of meat, and stuffed animals.

**Japan’s Faith-Based Approach to Death and Dying**

Ideas about life and death are strong aspects of people’s religious views. In a 2013 survey on the national character of the Japanese conducted by the Institute of Statistical Mathematics in Japan, 28 percent of Japanese reported to be religious and 72 percent non-religious (Toukei-Suuri-Kenkyujo 2013). However, even though most people in Japan do not subscribe to a particular religion, this does not mean there is a denial of the existence of gods or an outright disregard for religious events and customs. Rather, this has generally led to people feeling free to accept elements from any religion to a certain degree without being limited to a particular faith. Thus, it is not unusual for Japanese people to celebrate Christmas, to visit a Shinto shrine in the New Year, and to enter a Buddhist grave. Shinto, the most enduring faith in Japan, is not a monotheistic religion since it has a myriad of deities. Therefore, although it has been recognised since Buddhism was introduced in 552 that the Shinto gods and the Buddha are different (Ito 2012), there has been a natural continuation of the practice of concurrently accepting the different religions in syncretism, an example of which is the existence of shrines within temple grounds. In 1868 during the Meiji Restoration, an ordinance to distinguish Shintoism and Buddhism was enforced and the two religions were separated. Nevertheless, it is common even today for Japanese not subscribing to a particular religion to invoke both Shinto and Buddhist deities, uttering

---

6 During the Meiji Restoration, Japan opened the country to the outside world, ending Tokugawa Shogunate and their seclusion policy that had lasted for 215 years in the previous Edo era. The parliamentary system was formed with imperial restoration. Shinto became the core political ideology and the Emperor became a religious figure until the end of World War II.
“god (of Shinto)” and “Buddha” together at the same time when making a wish (“Kamisama Hotokesama”). While Christian angels and images of the Virgin Mary appear in Ninagawa’s *The Days Were Beautiful*, they are mere symbols of prayer for her father’s recovery and their presence is not suggestive of her allegiance to any particular religious belief. Ninagawa has said in an interview discussing her favourite objects that she is not a Christian, she just likes Christian statues (Hayashi 2015). She has also mentioned that she has a shelf that she calls a “corner of gods” in her library in her aforementioned office Lucky Star, where statues of all sorts of gods are displayed (Anazawa 2009).

Reincarnation is a Buddhist concept accepted by many people in Japan. While she is aware of the cycle of life and death, Ninagawa holds a vastly different notion from the idea of reincarnation, where the same spirit is continuously reborn.

My baby with a spirit of vitality and my father who slowly heads toward death. My newborn baby, my 80-year-old father and 43-year-old me in the middle.
This contrast and the gradation of life.
This is what connects lives. (Ninagawa 2017, 36)

For Ninagawa, the cycle of being born, giving birth, and dying represents the progression of life. She can see the contrast of life and death because she is midway between these end points with caring for her old and dying father and experiencing childbirth at virtually the same time, with her standing in the middle of the ‘gradation of life’, halfway between birth and death. This way of capturing the visualisation of life and death is characteristic of Ninagawa’s practice.

As suggested by the title of her photobook, Ninagawa portrays the event of her father’s death as beautiful. These words on the cover summarise its contents.

The day my father departed, the sky was so scarily beautiful.
Over 18 months, my father collapsed and slowly faded. Then, a blinding light, and the world became surprisingly beautiful.
A moving collection of photographs capturing those miracle-like days.
(Ninagawa 2017, front cover)

Ninagawa might have sensed something almost divine in her father who was leaving the human realm and approaching a different world. Furthermore, as written in the book, her father lived for 18 months after first collapsing in 2014, even directing as many as four plays in that time; thus, her father’s last year-and-a-half were “miracle-
like days” (2017, front cover). The decline in her father’s health coincided with the birth of her second son, so Ninagawa returned to her family home and was able to spend more time with her father. As she writes in her book, “That year-and-a-half after my father collapsed was truly like a present from God” (Ninagawa 2017, 64). In addition, by experiencing the workings of life with the simultaneous birth of her child and the death of her father, Ninagawa expresses in her image that life and death exist simultaneously as “beautiful”.

Cherry Blossoms as a Motif of Life and Death

Ninagawa’s photobook is wrapped up with these words:

Everyone truly does die.  
And I am here because of these connected lives.  
I am here now because people were born and died. (Ninagawa 2017, 79)

Next to these words is an image of cherry blossoms fluttering to the ground. The cherry blossom has been a popular motif of life and death since ancient times in Japan, as seen in many poems including those by the prominent poet Saigyo, who was a monk (Ishii 2003). Sayigo wrote “Negawaku wa hana no moto nite haru shinam Sono kisaragi no mochizuki no koro” [“Let Me Die Under Cherry Blossoms in Spring, Around That Time of February When the Moon’s Completely Full”] (1187). Ninagawa’s state of mind was similar to Saigyo when she stated “The sky was incredibly blue when I got up in the morning and it was beyond beautiful. I thought that such a day would be good if my father had to be gone” (Ninagawa 2017, 3).

The falling blossoms symbolise the end of the enchanting flowers, the end of life. In Ninagawa’s image, there is a bright light shining like a spotlight on the middle with the bottom right in darkness, alluding to the idea of moving from the light of life, to the darkness of death.
The book ends with a photo of her father’s final script, *Nina’s Cotton*, which he never had the opportunity to stage, opposite an image of shadows of Mika Ninagawa herself and her son who entered this world just as her father was leaving it. There is death and there is life.

Ninagawa is a unique contemporary photographer who creates work that extends beyond traditional styles in Japan. However, even Ninagawa’s work shows a Japanese sensibility in the way that she reflects its meaning of colours, religious attitudes, perspective of death, and death motifs such as cherry blossoms.
My Mother left Japan in 1989 and I left there in 2001. We have not been back to our home country for nearly fifteen years, but we still value our Japanese heritage. The influences of Japanese perspective can be seen in my work *Not So Soon*, and details are examined in Chapter 3.
Chapter 2: Methodology

In this chapter, four key factors are discussed in regard to the methodology of this research. Firstly, the metaphysical function of photography and its relationship to death is discussed. Secondly, relationships to and issues arising between visual research—photography in particular—and autoethnographic research are examined. Thirdly, psychiatrist Kübler-Ross’s ethnographic approach is discussed as a key influence. And lastly, visual works by contemporary practitioners working in various fields are analysed.

2.1 The Metaphysical Function of Photography and Its Relation to Death

To further explore issues of death and dying, I have adopted photography as a main tool of research since the metaphysical function of photography has been closely related to death. Susan Sontag (1977) explains in *On Photography* that photography is aggressive and that cameras are similar to weapons, likening them to guns. The camera requires one to ‘load’ the film, ‘aim’ the finder, and ‘shoot’ photographs.

> To photograph people is to violate them, by seeing them as they never see themselves, by having knowledge of them they can never have; it turns people into objects that can be symbolically possessed. Just as the camera is a sublimation of the gun, to photograph someone is a sublimated murder – a soft murder, appropriate to a sad, frightened time. (1977, 14-15)

Sontag also claims that everything captured by photography becomes nostalgic. This is because “All photographs are memento mori”, and “to take a photograph is to participate in another person’s (or thing’s) mortality, vulnerability, mutability” (1977, 15). There is thus a schism in her thinking about photography that includes both the question of its violating power as well as its more humanising power as a technology, which captures and allows us to pay attention to the human condition of inescapable death and loss. Photography captures a moment that never occurs again, and records what is disappearing. Therefore, “a photograph is both a pseudo-presence and a token of absence” (1977, 16). The moment captured in a photograph exists no longer, and so to take a photograph is the same as capturing the moment of death.
French literary theorist and philosopher Roland Barthes examines photography in his book *Camera Lucida* (1980). According to Barthes (1980), the nature of photographs—"noeme" as he calls it—is “That-has-been” and was once there, but not existing any longer. Another argument introduced by Barthes that relates to death and photography is that photography as an art is not similar to painting but rather to theatre. He points out that the birth of theatre was closely related to death and dead people, using the example of Nogaku (Noh), a traditional form of Japanese theatre that started around the fourteenth century (The Nohgaku Performer's Association n.d.). Nogaku was developed not only as an entertainment but also as a dedication to the Shinto God and to mourn for the dead. Barthes claims that people in photographs often seem to be active and alive, but we can see death lying underneath their masks, the same as in Nogaku at a theatre.

Historian and theorist Geoffrey Batchen’s text *Burning with Desire* (1999) examines a series of images created by Hippolyte Bayard in 1840 titled *Le Noye*. Bayard captured three variations of self-portraits, mimicking a drowned man. Batchen claims that this photography, made in the very early stages of photographic history, provides some of the most significant images in the history of photography, as they were “all about the practice and implications of photographic representation in general” (1999, 171). According to Batchen, photography represents “sight and blindness, absence and presence, life and death, construction and ruin” (1999, 172). He goes on to explain that photography is like a footprint or a death mask, and it is a reference to the newly departed from its original (1999). Therefore, as an indexical trace of life, there can be no better medium with which to capture the traces and marks of death and dying than photography.

### 2.2 Photography and Autoethnography

As Patricia Leavy claims in her Book *Method Meets Art* (2009), the creative arts can serve, refine, and expand the work of other qualitative research undertaken in social science practices. Creative practices can also provide new questions to be asked, making highly effective methods to describe, explore or discover. Creative practices such as photography evoke emotional responses, leading to a raised awareness of social issues. Therefore, photography can give a voice to ‘subjugated perspectives’ by
accessing personal narratives and promoting dialogues. Photography-based research can reach audiences outside of academia as well, connoting multiple meanings and representing many voices (Leavy 2009).

Photography is a method traditionally used in research disciplines such as anthropology, ethnography, and sociology, including recent disciplines of visual sociology and visual ethnography. Photographer and sociologist Douglas Harper employed the qualitative method of visual sociology to document the disappearing culture of the tramp, publishing the book *Good Company: A Tramp Life* (2006) after spending an extensive period of time with homeless people. Harper claims that contemporary visual sociology requires a lengthy involvement with subjects, rather than a short period observing them, and that there has to be collaboration between the researcher and the subjects.

Visual ethnography is a useful approach when considering how photography can be developed as research. Sarah Pink states that “ethnography is a process of creating and representing knowledge (about society, culture and individuals) that is based on the ethnographer’s own experiences” (2013, 35). In her book *Doing Visual Ethnography* (2013), Pink states that photography was once utilised to support text-based information among anthropologists and ethnographers, but it is now widely accepted to consider sensory information, including visual images, as knowledge (Pink 2013). Pink also points out that it is impossible to define differences between ethnographic images and documentary images in terms of its form, content, or potential; however, images in ethnographic research are focused on “[how image] is situated, interpreted and used to invoke meanings and knowledge that are of ethnographic interest” (2007, 35).

This research used an autoethnographic-based approach. According to researcher Heewon Chang, autoethnography is a combination of cultural analysis and interpretation with narrative details (Chang 2008). Consequently, it concentrates on self-narrative to understand one’s self and provides a window through which to understand others.
Family members have been the focus of some autoethnographic research, such as Carolyn Ellis’s *With Mother/With Child: A True Story* (2001) and Marissa Joanna Doshi’s *Help(less): An Autoethnography about Caring for My Mother with Terminal Cancer* (2014). Akemi Kikumura, who is an anthropologist and a second-generation Japanese-American, studied her mother’s life story. Her mother was an Issei (first-generation) Japanese woman living in America. Kikumura explains that because she was not an Issei herself, she was an insider as a member of family, but an outsider at the same time (Kikumura 1981). Being a Japanese migrant living in Australia for about twenty years, I sympathise with Kikumura’s position, where I am an outsider as well as an insider to Australian society. I also occupy the position of being an insider as a member of family researching my Mother’s state, and being an outsider by observing my Mother in an attempt to understand what she is experiencing with her sickness.

Autoethnography researchers Arthur Bochner and Carolyn Ellis (2003) explain that autoethnographic art shifts traditional research from a passive to a transgressive activity:

> [Art is] not something to be received but something to be used; not a conclusion but a turn in a conversation; not a closed statement but an open question; not a way of declaring “this is how it is” but a means of inviting others to consider what it (or they) could become. (Bochner and Ellis 2003, 507)

However, Chang warns of the five pitfalls of autoethnography:

> excessive focus on self in isolation from others; (2) overemphasis on narration rather than analysis and cultural interpretation; (3) exclusive reliance on personal memory and recalling as a data source; (4) negligence of ethical standards regarding others in self-narratives; and (5) inappropriate application of the label “autoethnography”. (Chang 2008, 54)

It is clear that autoethnographic research requires academic rigour and analysis of the subject/s as well as others, society, and culture. Brydie-Leigh Bartleet, who adopts autoethnography for her music research, discusses the balance of artistic and aesthetic concerns and research, especially when the researcher is inadequately accomplished in creative arts. Artful autoethnography demands aesthetic value and, without creative substance, it fails in this mode of inquiry (Bartleet 2013). Therefore, text-based analysis and visual inquiry are both equally significant for photographic research based on autoethnography. Photography is often used as a medium of communication, and
photo elicitation is one of the research methods used to generate responses of the informants by showing photographs during their interviews, eliciting comments (Schwartz 1989). In many cases, researchers do not take photographs themselves, using photography taken by the subject or others. In those cases, technique is not often their main focus. Some researchers adopt photography and attempt to capture the images by researching themselves; however, their images have still played a supporting role and become illustrative of their texts. In some research, snapshots are simply presented, rather than focusing on aesthetic significance. Some visual art researchers present photography from the perspective of sociological inquiry; however, they often omit text-based analyses. Only a very few practitioners have successfully combined research texts and strong visual semiotics. With a university education in photography and communication, and experience in the media industry as a writer and photographer, I am equipped to contribute to this gap, joining only a few visual arts researchers who regard both significant texts and photography on death and dying to communicate to the broader public.

2.3 Kübler-Ross’s Ethnographic ‘Storytelling’ Approach

Kübler-Ross’s book On Death and Dying (1970) is one of the most influential texts on terminal and palliative care; however, her theory, especially the “five stages of death”, became controversial among other researchers. Michele C. G. Chaban (2000) conducted research and pointed out some failures of Kübler-Ross’s research. Michiko Aoyagi also argues Chaban’s views in her paper “The Thought of E. Kübler Ross and Its Criticism: The Criticism by Chaban” (2005). One of the key criticisms is the linear structure of the five stages; however, Kübler-Ross explained in subsequent publications that she did not mean to present the stages in order, declaring the

---

8 See, for example, Clive C. Pope, My Dirty Story about Gardening: A Visual Autoethnography (2016).
9 See, for example, LaToya Ruby Frazier The Notion of Family (2015).
attitudes of people dying are very individual and that not everyone goes through every
stage (1975; 2005).

Despite the issues raised by some researchers regarding Kübler-Ross’s theory, it is not wise to underestimate the ethnographic approach that she applied. Of her book, Kübler-Ross states,

it is not meant to be a textbook on how to manage dying patients, nor is it intended as a complete study of the psychology of the dying. It is simply an account of a new and challenging opportunity to refocus on the patient as a human being, to include him in dialogues, to learn from him the strengths and weaknesses of our hospital management of the patient. (Kübler-Ross 1970, 140)

She introduced many individual stories of patients gleaned from a number of interviews and treated them as exemplars. This approach of ‘storytelling’, also often adopted by visual artists, is effective when trying to connect with a wide range of people. It is both intimate and makes it easier to reflect upon our own lives rather than displaying the numbers of research statistics. In fact, Kübler-Ross is one of the most successful researchers in this field of death and dying inquiry, connecting with not only medical practitioners but also the general public through her seminars and books. Kübler-Ross also created a documentary book To Live Until We Say Goodbye (1997) which was illustrated with photographs of her patient Mal Warshaw. This book captures individual stories of dying people and their families, revealing their fear of death, agony, grief, how they lived, and how they tried to find peace of mind as they faced death. This work shows not only the processes of these people but also their emotions, which we access by looking into the eyes of those in the photographs.

I conducted this photography project and research on my Mother by applying a similar approach to Kübler-Ross, analysing my Mother’s perception of death and dying and her process of living with terminal illness through ‘storytelling’. The results of this will be discussed further in Chapter 3.

2.4 An Analysis of Visual Practitioners’ Inquiries into Death and Dying
As part of my research for this practice-led doctorate, I have investigated a vast range of fine art, photography, and film artists; however, only a few prominent
contemporary works are introduced here in order to establish a contextual survey that demonstrates the exploration of death and dying by acclaimed photographers and visual artists. I will examine selected visual practitioners in two different categories: visual practitioners in various creative fields and visual practitioners in documentary photography practice.

2.4.1 Visual Practitioners in Various Creative Fields

Mami Sunada *Ending Note* (2012)

*Ending Note* (2011) is the debut documentary film directed by Mami Sunada, in which she captures the last days of her father’s life following his battle with cancer. Sunada uses a voice-over to narrate the film and it is uniquely acted by herself as her father who has now died. It became a box office success in Japan, which is very rare in Japan’s non-fiction film industry. In the film, the father goes to great effort to prepare for his death, mirroring the same approach that made him a hard-working Japanese businessman. Sunada describes herself and her family’s pain in a very subtle, humorous way throughout his last journey. This work succeeds in expressing the sensitive issues of death, loss, and grief without overwhelming the audience.

Documentaries are filmed most often from a third-person viewpoint. However, Sundada took an unusual approach in which the inner thoughts of the father’s mind were performed by Sunada herself, making it clear that the voice being represented was projected from Sunada’s point of view as the third person. This makes the audience aware of Sunada’s love for her father and her attempts at trying to understand him. However, one of the remarkable aspects about this movie is Sunada’s objectivity. Sunada captures her father and family members in a very calm manner during this emotional time, facing her father’s death. The father opens his mind and talks to Sunada behind the camera frankly, but Sunada keeps a certain distance through the lens as a third person. Her own emotion is concealed, and she comprehends any event from a director’s perspective as well as that of the audiences. Hosokazu Kore-edo, the producer of this film, is a prominent Japanese film director whom Sunada used to work for as an assistant. He explains why he decided to support her movie, claiming that the distance between the subject and the director, her acute approach, and love as a subject are all integrated very well in a good balance.
(Nakayama 2011). Sunada’s objectivity differentiates her work further from ordinary home videos. Such an approach is essential in conveying a story as a creator of any kind to deliver the message to an audience.

![Figure 19. Mami Sunada Ending Note poster 2011](image)

**Walter Schels and Beate Lakotta *Life before Death* (2008)**

For *Life before Death* (2008b), Walter Schels and Beate Lakotta took portraits of twenty-six people at hospices in northern Germany who were very close to death, and they also took the same people’s portraits posthumously in a similar composition. Their work was displayed as diptychs—alive on the left, dead on the right—almost like mirror images. One of the subjects, Heiner Schmitz, claimed “No-one asks me how I feel, because they’re all shit scared” (Lakotta 2008a). Schels and Lakotta address and confront the question of the social taboo of death in terms of its representation in meaningful ways and in terms of eliciting or opening up meaningful conversation around our mortal existence. People die at institutions nowadays and many people do not know what a deceased person looks like or what they feel like if touched. However, death will equally come to every one of us, and people are terrified due to a lack of knowledge or experience with the deceased. Lakotta believes that once the audience sees their work, they will realise the exhibit is more than just shocking images. Colin Martin (2008) states that Schels and Lakotta’s work has “a spiritual intensity that is ecumenical; encompassing all religious beliefs and non-believers” (2008, 1496). The idea of post-mortem photography normally shocks and terrifies people; however, Schels and Lakotta’s work succeeds in suggesting to the audience how to deal with and overcome the fear of death. Their images are quite intimate and calm, revealing a transition of our life with a notion of peacefulness.
Artist Sophie Calle lost her mother, Rachel Monique, in 2006. Her mother had three other names during her life, and left sixteen diaries dated from 1981 to 2000. Calle held an exhibition firstly at Palais de Tokyo in 2010, at Eglise des Celestins in Avignon in 2012 as a part of Festival d’Avignon, and at Episcopal Church of the Heavenly Rest in New York in 2014. The book *Sophie Calle – Rachel Monique* was published in 2013 (Calle 2013). The details of the exhibition are slightly different depending on the venue, but always included was a film of Calle’s mother on her deathbed, some photographs and other artworks such as objects that look like plaques from a graveyard, and objects with the text ‘souci’ (meaning ‘don’t worry’) from her mother’s last words. Calle also read excerpts from her mother’s diaries to the audience as a part of the exhibition. These diaries were not written to be exposed to the public, and they reveal the love and very personal life of her mother (2013). The audience are invited to share in Calle’s experience of peeping into her mother’s secret diary as she tries to comprehend who her mother was through its contents. Calle beautifully weaves death, identity of self, and the mother figure through the artworks and ritual of installations beyond ordinary melancholic nostalgia. In this way, Calle contributes to universal questions what defines the identity of living or dead people, and what death means.
2.4.2 Visual Practitioners in Documentary Photography Practice

**Briony Campbell The Dad Project (2009)**

Briony Campbell is a London-based photographer and filmmaker. Campbell created *The Dad Project* (2009) for her Master of Arts at London College of Communication, capturing her dying father during his last six months with a documentary video and photographs.

Her father had become sick with cancer and was told that there was no further treatment available. Nevertheless, both she and her father tried to stay optimistic at the beginning of their journey, and she started this project because she knew “that by doing *The Dad Project* we could look at the half-full glass together” (Campbell 2014, 240). It was a collaborative project with her father’s full support and willingness to participate. Campbell gradually realised her and father’s emotional struggles as well as her creative challenges. She wondered, “Would I just end up with a pile of gentle images about a dad dying a little too early of an all-too-common death; images too sad for my family and too ordinary for an audience?” (Campbell 2014, 244). Campbell
further recalls that “When I tried to view my images objectively I thought, though they
looked rather ‘safe’, they were at least honest” (Campbell 2014, 246).

Her images are very subtle yet powerful because of their candour. Campbell confesses
that she swept up the glass when her father dropped his milkshake, choosing to miss
the moment and afterwards only taking a shot of the stain on the floor. She says in the
caption of the image that “Perhaps I’d proved (to myself or my parents? I’m not sure
which was the necessity) that I was a daughter before a photographer” (Campbell
2009). She also admits later in her paper that she felt “dangerously close to narcissism”
(Campbell 2014, 243) when she took a self-portrait of herself crying. Eventually, she
realised that images of her parents’ house felt sadder than her self-portrait showing
narcissistic clichéd emotions (Campbell 2014). Campbell’s honesty is evident in her
poignant closing image of her holding her father’s pallid and lifeless hand. She recalled
in an interview with The Guardian that she could not tell the difference between the
images she took of her father’s hand before his death and after, and so she does not
remember which one is which (Hattenstone 2010). This frankness indicates how sad it
is to have someone on their death bed still alive, to have their last moments already
shadowed by death.

Being open with oneself is challenging, yet it is essential in any kind of creative work
that will arouse raw feelings in others. Campbell’s attempt to capture her and her
father’s journey is genuinely personal, revealing each of their days from her own
perspective. Thus, her work is touching and has the power to make people recall and
reflect on their own experiences.

Figure 22. Briony Campbell Eating Dad’s dinner (from the series of Dad Project) 2009
**Phillip Toledano *Days with My Father* (2010)**

Documentary photographer Phillip Toledano started a project in 2006 after his mother died and he started taking care of his aged father. He began capturing the final days of his father, who was suffering from memory loss. He states in his book that “This is a journal. An ongoing record of my father and of our relationship. For whatever days we have left together” (Toledano 2010). This work contains many images taken with a shallow depth of field and ambient lighting, creating soft and warm impressions. Most things in the images are blurred, mirroring Toledano’s state of mind as he tries to focus on a tiny glimpse of truth or love that exists even in an overwhelmingly difficult situation. In his talk in 2017 at a CreativeMornings event in New York, Toledano clearly claims that his project was not about death, dementia or sadness, but love: “This work, *Days with My Father*, is a love letter from me to my dad” (Toledano 2017). His images depict his love for his father and suggest that nothing else is critically important to him.

Toledano also incorporates a little humour into his work, showing his father’s prank with meringues on his chest like nipples or his father sleeping with a funny eye mask. Humour, which is also employed by Mami Sunada in her work (as mentioned in 2.4.1), is very effective in successfully presenting the sensitive issues of death, loss and grief without overwhelming the audience.

Toledano went on to create other projects related to death: *When I Was Six* (2015b), the subject of which is the memorabilia of his sister who had died forty years earlier, and *Maybe* (2015a), which looks at his possible future as an aged man and his own death. His exploration of death and dying expanded after *Days with My Father* and Toledano claims, “In some ways, death is an extraordinary gift because it gives you an opportunity to look at things,” and “death is not the point of my work, but it’s been the start of a lot of work. And even though it brought me extreme sadness, it’s also given me an incredible sense of clarity and gratitude” (Toledano 2017).

Toledano began with documenting his father’s last days, and eventually progressed to be more reflective in later works. It is interesting to observe how his way of capturing his subjects shifted, from an authentic un-staged documentary style with *Days with My*
Father to gently arranging his sister’s memorabilia with *When I Was Six*, and then fully staged photographs, almost like film shoots, with *Maybe*.

As he further reflects on his own perspectives, he expands his non-fictional creativity. Toledano’s attempt in *Maybe* took a very similar approach to *Le Noye* created by Hippolyte Bayard in 1840 (discussed in Chapter 2.1), beautifully depicting death and absence, and compelling the audience to contemplate their own mortality.

---

**Figure 23. Philip Toledano *Days with My Father* 2006**

---

**William Yang *Sadness* (1992)**

From the late 1980s to early 1990s, third-generation Chinese-Australian photographer William Yang created a photographic series entitled *Sadness*. It premiered as a performance piece, consisting of slides and a monologue at Belvoir Street Theatre in Sydney in 1992 before going on to tour nationally and internationally. His book of the same title was published in 1996 (Yang 1996), and a documentary video *Sadness* (Yang and Ayres 2009) was also created, directed by Tony Ayres. *Sadness* showcases Yang’s photographic work, which captures his friends dying of AIDS, his family, and his own search for his identity through the discovery of the truth about his murdered Uncle. Curator Helen Ennis asked Yang why he photographed dying friends. Ennis reportss, “He was curious about the way people approached their own deaths because he saw dying as a ‘test’ or an ‘appraisal’ of how they lived” (Ennis 2007, 34). Ennis also points out that Yang is an insider as a former lover or a friend of his subjects; thus, *Sadness* also documents his own journey without the cloak of objectivity. Yang’s personal commentary is often handwritten alongside or even directly on to the images. In *Reveries* (2007), which Ennis curated, explanations of Yang’s ex-partner Allan’s
condition and journey at the time were displayed underneath the images along with Yang’s own reflections of his personal memories and feelings. Some images show the subject in a coma, and included is a post-mortem image of Allan on his death bed, revealing the last moment of his life. However, none of those images are overly melancholic or ironic; they only depict death existing as an inevitable truth, even as Yang’s feeling of sadness is explicit. In her paper “Stillness and Intrigue in the North and Sadness by William Yang”, Helena Grehan (2002) claims that what is most salient about Yang’s style is his stillness: “He continually maintains the position of narrator, seemingly distant yet present...in a way that also allows for the spectator’s entry in to the performance” (Grehan 2002, 151). With this stillness, spectators “can project, interpret and contemplate” (Grehan 2002, 152). Although Yang’s stillness is seemingly observational and less emotional, the way in which he captures the image is not at all distant from the subject.

One image depicting the last moment of Allan’s life as he is in coma illustrates this approach clearly. Allan’s face is gaunt, and his one visible eye and mouth are half open, devoid of life. For this image, Yang stood face to face with Allan’s impending death, not looking away but rather capturing the subject’s lifeless eye in the centre of the frame. Yang’s powerful images look straight at the subject, capturing them with stillness, even though the subject is the imminent death of a loved one. This is a tremendously hard thing to do.

![Figure 24. William Yang Allan (from the series of Sadness) 1990](image-url)
Yang’s handwritten texts are greatly effective in adding authenticity and intimacy to his works. Ennis (2007) also points out that his texts explore the complex notion of time. The past moment is sealed in the image (as discussed in Chapter 2.1); however, time goes on outside the picture. Accompanying texts handwritten by Yang are a reflection from a later time and added to the past of the image.

Photographs often become objects of mourning and trigger memories beyond the frame, as Margaret Gibson states in her book *Objects of the Dead* (2008). The photograph itself does not necessarily hold the memories; rather, it often becomes a bridge that connects the past to the present. Helena Grehan and Edward Scheer explain in their book *William Yang: Stories of Love and Death* (2016) that these handwritten texts open a dialogue between the photographer and audience: “[Yang’s] confessional does more than simply describe a feeling or memory, but activates an attitude around it. The confession implicates the person to whom the information is offered as a witness who must also bear responsibility for this shared knowledge” (Grehan and Scheer 2016, 121). These handwritten texts prompt and encourage people to celebrate their own memories.

Yang’s approaches significantly influenced my final visual project. I tried to capture both my mother’s impending death and our mother–daughter relationship in a subtle and still manner without looking away. My images are also accompanied by handwritten texts in Japanese and English to add my true voice and to inspire dialogue. I have not, however, superimposed my images with the texts like Yang did. Indeed, Yang’s texts merge into the images beautifully, often enhancing the contour of the subjects; however, I chose to leave my images as they are, instead placing the explanations on the wall beside them. This way my voice becomes a stepping stone to developing more dialogues instead of risking becoming a label and limiting the power of the image too much.

As described in this chapter, many artists are concerned with breaking through the taboo of death and exposing our discomfort at looking at real life death as a form of critical social practice. Many artists try to capture the death of others, aware of the troubling issues or ethics in representing deceased people. Sunada captured her father
with remarkable objectivity; Schels and Lakotta prompted us to question our mortal existence; Calle contributed to discussions on what defines the identity of dead person and what death means; Campbell pursued her project with great honesty; Toledano expressed love with his images using ambient light; Yang looked unwaveringly at the subject up close, to capture them with stillness, even though the subject was the imminent death of a loved one. Their work moves us because they reach beyond curiosity, melancholy, shock, fear or the agony of death, showing the facts of death as they are, with a calm perspective which can only be reached after experiencing overwhelming emotions by facing death in reality.

It is not an easy task to create such images. In the following chapter, I outline my attempt through *Not So Soon* to capture what the artists discussed in this chapter have achieved in their work.
Chapter 3: Not So Soon

My Mother, Masako Katayama, was born in Osaka, Japan, in 1949. She married at the age of twenty and gave birth to me in Tama City, Tokyo, in 1971. She left our family when I was fifteen after a long, painful, and strained relationship with my father and moved to the Gold Coast in 1989. I visited her once or twice a year sometimes only for a week and sometimes for a longer period, including a semester spent studying at Griffith University in 1995. I was instantly drawn to the beautiful climate, the nature, and the people of the Gold Coast, and decided to move there permanently in 2001.

My Mother was first diagnosed with very early-stage breast cancer in 2008 and then with the last stage of ovarian cancer in June 2014. I started documenting her days at both the hospital in 2014 and at home with still photographs as data collection and field notes using an HDSLR camera.

Observing the commonly adopted rules and ethics of international competitions such as the World Press Photo, my images are not digitally altered. Following these guidelines, I do not remove or replace unwanted objects or change shapes. Instead, I choose only to enhance colours, brightness and contrast which are similar to the traditional methods in a dark room printing since the film camera era. All images except for the portraits are unstaged. I consider the honesty of my images as a very significant foundation to engage with my intended audience. Most images are captured with ambient lighting, in a personal environment, in order to express the intimacy of the moment. These strategies have been adopted to develop a personal visual language in response to representations of death and dying. The analysis of visual practitioners discussed in Chapter 2.4 demonstrates how they embrace their own strategies to avoid overly emotional images. In doing so, audiences are enabled to reflect on their experiences and emotions.

After outlining my methods, this chapter will analyse this project, which are as follows: a video work captured her interview investigating my Mother’s fear of death; a solo exhibition held in Sydney that featured a diary exchange project, which extended our exchange from image to image and text; an analysis of our mother–daughter relationship; a group exhibition and our state of limbo between Australian and Japanese culture.
3.1 Fear of Death and Video Interviews with My Mother

As a way of dealing with the impending death of my Mother, I decided to analyse her perception of death and dying. In July 2015, about a year after she was diagnosed with ovarian cancer, I interviewed my Mother, using two fear-of-death questionnaires to guide me.

Fear of Death

Ernest Becker begins his book *Denial of Death* (1973) with the following statement: “The idea of death, the fear of it, haunts the human animal like nothing else; it is a mainspring of human activity” (1973, xvii). Becker points out that children learn fear of death from parents and society through their development, although fear of death is also our basic instinct as a biological and evolutionary function to maintain life thriving to the next generation. Nevertheless, people cannot live functionally when the fear is present all the time. We need to put death into the background of our consciousness in order to go about our everyday life with a sense of security; therefore, we try to control our fear of death through repression. People tend to avoid the topic of death, constructing it as morbid. This results in the pathologising of those who may wish to open such a conversation. Becker writes about the hero figure who in battling against the evil character in the story is really fighting against death. Evil is therefore understood as death in disguise. The evil character brings death, danger, and destruction to the world, and the hero, in ultimately conquering and vanquishing the evil character, pushes the risk of death away to overcome fear of death. The hero is almost always male, and this aspect of death culture is something I note but am not able to take up further here. However, in writing about my Mother’s diagnosis and experience of facing her mortality, I am giving representational value to women. In popular culture, the heroic death is often embedded in narratives of violence but it can also be imagined and represented in entirely different ways, where there is bravery and fear as death is faced in ordinary contexts and situations. This is where my project is situated. Death gives life meaning: it drives human beings towards creativity and cultural activities which can endure over time and can gain immortal status. Becker
draws upon psychoanalyst Gregory Zilboorg (1943) to say that the fear of death is an “expression of the instinct of self-preservation” (in Becker 1973, 16).

Research by V. L. Bengtson, J. B. Cuellar and P. K. Ragan (1977) shows that anxiety towards death decreases as age increases. However, B. V. Fortner and A. Neimeyer (1999) discovered that some older adults in certain categories feel a heightening in their fear of death.

Death anxiety was heightened for older adults who (a) had more physical health problems, (b) reported a history of psychological distress, (c) had weaker religious beliefs, and (d) had lower “ego integrity”, life satisfaction, or resilience. Moreover, place of residence also predicted death concerns: those living in institutions (e.g. nursing homes) were generally more fearful of death than those living independently. (Fortner and Neimeyer 1999 in Neimeyer, Wittkowski, and Moser 2004, 314)

Neimeyer, Wittkowski and Moser (2004) claim that the elderly show less fear of death or dying than the middle-aged but not more than young people. They also point out that individual interpersonal factors (e.g., coping styles and religious beliefs) and personal resources (e.g., social support) largely affect one’s fear of death rather than sickness or age. To consider fear of death in a particular case, it is necessary to understand the background information of the person in question.

Fear-of-Death Scales
To measure detailed factors of the fear of death, a number of fear-of-death scales have been developed. For example, the Fear of Death Scale was constructed by Jerome Boyar (1964) and the Death Anxiety Scale (DAS) was developed by Donald Templer (1970). Jon W. Hoelter (1979) merged and extended these two scales into the Multidimensional Fear of Death Scale (MFODS), composed of the following factors: fear of the dying process; fear of the dead; fear of being destroyed; fear for significant others; fear of the unknown; fear of conscious death; fear for the body after death; and fear of premature death. Taking an approach similar to Hoelter, Ahmed M. Abdel-Khalek (2002) developed the Reasons for Death Fear Scale (RDFS)11 with more detailed factors including items of fear of self. Another measurement, the Collet-Lester Fear of Death Scale (CLFD), was introduced by Lora-Jean Collett and David Lester (1969). The

11 See Appendix 2.
CLFD has been revised a few times, and Lester and Abdel-Khalek presented the Collett-Lester Fear of Death Scale version 3.0 (2003), deleting four subscale items and changing wordings in some items. The CLFD is well developed to examine four different factors distinctively: own death; own dying; others’ death; and others dying. Each category consists of seven sub-items in detail.

When I was constructing the interview questions to examine my Mother’s perceptions of death and dying, I found the RDFS (2002) and version 3.0 of the CLFD (2003) very useful, even though these questions are not designed to be used in this way. The RDFS is well structured; however, most of the items listed in the CLFD were not included (only two items were overlapping). Despite the useful function of examining the comparison between the fear of one’s own death and the fear of the death of others in CLFD, only ‘Own death’ and ‘Own dying’ were examined in this research to focus on my Mother’s own fear when she realised that her imminent death was becoming more real. I asked my Mother to rate on a scale from 1 to 5 how disturbed or anxious she felt about each aspect of death and dying, with 1 being ‘Not anxious or disturbed at all’ to 5 being ‘Very anxious or disturbed’. Despite my Mother’s fluency in English, all the interviews were conducted in Japanese to let her relax and to give genuine answers. The response and answers were required to be instant and to provide first impressions. After my Mother provided numbers for each of the questions, an interview was held to discuss how my Mother felt about the aspect and why she had responded with a particular number. Some additional interviews were conducted after finishing all the prepared questions to investigate her fear of death further.

---

12 See Appendix 3.
13 Item numbers 6 and 15 of the RDFS (‘Leaving behind secular pleasures’ and ‘Acute pains associated with dying’) overlap with numbers 3 and 9 of the CLFD version 3.0 (‘Missing out on so much after you die’ and ‘The pain involved in dying’).
14 See Appendix 4.
15 See Appendix 5 and 6.
Plate 1. Yoko Lance After the surgery (from the ‘Not So Soon’ series) 2015

My Mother Masako’s Perception of Death and Dying

The highest scores recorded for my Mother’s anxiousness or fear were to questions regarding her offspring and loved ones. However, the fact that the interviews were
conducted by me, her daughter, must be taken into consideration in terms of the results. My Mother explained, “I feel bad about the pain I’ll cause. That’s what scary, not dying. I just feel sorry about that. So [if I correct what I said,] I’m not scared, but I’m sorry.” My Mother showed sympathy towards our family, but she also said “we have to be apart one day, so there is no point worrying about when it will be. It could be tomorrow or a hundred years later.”

Returning to the pluralism that exists in Japanese faith practices as discussed in Chapter 1, some of the religious aspects of Japanese people living in Australia must be considered in order to analyse my Mother’s religious attitudes. During the interview, she explained “I do not have any particular faith toward any religious organisation, but I do accept all religions at the same time.”

Overall, it seems that my Mother accepts her own death and dying, as evidenced by the low scores given for many answers. At the time of writing, it has already been a year since my Mother had to undergo surgeries and chemotherapy, and she must be at a stage of acknowledging that death is not a remote idea but a reality, and so she is ready to accept some aspects of death and dying.

I witnessed a similar attitude in my friend Eddy Stone, whom I documented in a previous project titled Captain Eddy (Lance 2012). When I met him, Eddy was a retired British migrant who lived on the Gold Coast who had been diagnosed with incurable cancer that had spread all over his body. I conducted an interview with him about fourteen months after he had been diagnosed. During the interview, he was very calm about his situation and the fact that his life was to end soon. He said, “I’m just gonna enjoy myself, and treat my life as if I’m gonna live forever.” He was accepting of the fact that he was dying. At the same time, he was trying to suppress his fear of death, and tried to ignore it as if his life were not about to end.
Even though my Mother seems to have accepted her destiny already, the pain associated with the dying process is still a significant fear for her. In my Mother’s interview, she said “I am scared of pain. Please get rid of the pain”, “Please forgive me and don’t make me suffer”, “I don’t want to die in pain. I hope I could die while I’m sleeping.” She also has a fear of ‘living’ with no physical abilities, and being rendered immobile: “It will be the hardest thing if I have to live lying in bed with a lack of physical abilities. If I cannot move nor talk, that will be my biggest fear... I hope I would die soon [if I was in that situation].”

My Mother also mentioned that she does not care about her body degenerating after her death; however, she does not want to see herself getting old and ugly while she is still alive: “I feel my energy is very low and I can see my body is degenerating at the moment (faster than healthy people). I don’t like to become decrepit and ugly with age and I don’t want to see it with my own eyes, definitely.”

As discussed in Chapter 2, Kübler-Ross focused on listening to dying patients and their stories. The participants described in Kübler-Ross’s research frequently showed signs of going back and forth between accepting and fearing death (Kübler-Ross 1970; Kübler-Ross 1975; Kübler-Ross and Walshaw 1997; Kübler-Ross and Kessler 2005). Even Kübler-Ross confessed that she became disappointed when she realised that she was not going to die sooner rather than later when she was paralysed and lost her mobility due to her stroke (Kübler-Ross and Kessler 2000). She was ready to die, but she was not ready to accept dying slowly in pain despite the fact that she was such an important internationally recognised researcher and advocate of death and dying education. Her work with the dying and their families in the 1960s in American
hospitals was important in challenging the taboo of death through education. Indeed, she argued that the dying have a lot to teach doctors, psychologists, and social workers about the experience of dying in the modern institutional setting, where saving people from death often burdens the dying, who mostly want a peaceful death. I note a similarity here to Herman Feifel’s research conducted on World War I veterans who experienced facing their own death in extreme conditions. War veterans also responded unanimously that they would prefer to die in their sleep (Feifel 1956 in Fortner and Neimeyer 1999).

Based on this research and the outcomes of my Mother’s interview responses, I created a video piece as follows.

**Not So Soon Video**

In 2015, I assembled some parts of the interviews and photographs taken of my Mother up to date into a video titled *Not So Soon* in 2015. To determine which part of the captured videos should be in the final edit, I firstly divided her interviews into five different categories: acceptance of death; fear of pain; fear of living in an undesirable state; religious aspects; thoughts about her family.

![Figure 26. Yoko Lance transcript 2015, categorising the transcript with five colours](image)

However, I tried to transform these results into a visual work without showing an obvious trace of research analysis to let the audience ‘feel’ my Mother’s perspective intimately, instead of analysing her together with me. This video montage featuring
still images and audio captures the moment of ‘she-has-been’, as discussed in Chapter 2, and it operates as homage to her strength and her journey, giving voice to a mother who is courageously facing her mortality.

Plate 2. Yoko Lance Not So Soon (video) 2015, 6:58 min
To watch this video, see http://www.yokolance.com.au/notsosoon/
Plate 3. Yoko Lance Losing hair (from the ‘Not So Soon’ series) 2015

Plate 4. Yoko Lance Still smoking (from the ‘Not So Soon’ series) 2015
Plate 5. Yoko Lance Resilience (from the series 'Not So Soon') 2015
3.2 Diary Exchange Project and Not So Soon, at Head On Photo Festival, Sydney

The Not So Soon exhibition was held between 3 and 14 May 2016, at Depot II, 2 Danks Street Gallery, Sydney, as a part of the Head On Photo festival. I also produced an online exhibition so viewers who could not attend or wished to revisit the work could witness the exchange. This can be viewed at:


For this exhibition, I used some of the texts emerging from a diary exchange project between my Mother and me. A Japanese blog was created to exchange our messages in a diary-blog form. Short sentences were extracted from these texts and displayed on the wall alongside the images to amplify the aesthetics, letting the audiences see, read, question, think and feel, as well as to consider their own responses in a similar situation. At the exhibition, my Mother had the opportunity to receive direct feedback from visitors during the period in which she minded the gallery. She was touched to witness their empathy and support, reporting one older man who gave her a warm cuddle with tears in his eyes. The text accompanying the images was printed on tracing paper, with all texts displayed in both Japanese and English. This idea was originally aimed to deliver to audiences in both languages; however, the process of presenting the messages bilingually made me reconsider my identity as a Japanese Australian.

The process of assembling works for the exhibition clarified what I truly wanted to express through the project: that receiving a cancer sentence is cruel, but my Mother and I have been granted one last chance to cherish our remaining time together.

---

16 See Appendix 7.

Plate 8. Yoko Lance Not So Soon Sydney exhibition – text 01 2016

Texts on the wall (Plate 8):

I wonder if people who die without knowing their

time is up are fortunate or not?

Texts on the wall (Plate 9 & 10):

Getting a cancer sentence is cruel. No doubt about it. But for people diagnosed with cancer, perhaps they have also been given a last chance at life.

How will you live the rest of your life?

How will you spend the last of your time that’s left?

That may be the last chance at life granted only to someone who has had the crushing experience of being confronted with their own death.

I as the daughter have also been given the lucky or unlucky chance to think about Mum’s death and the remaining time I have with her.

Sooner or later everyone dies.

If I’m going to have to accept the fact that my mum will one day die, then, until that time comes, I want to be grateful for being given the chance to spend that time with as few regrets as possible.
Texts on the wall (Plate 11):

Mum says she’s not scared of death,
just scared of the pain and suffering at the end.
I want to be able to fulfil my mum’s wish to be
spared of that, just that, no matter what.
Texts on the wall (Plate 12):

Thank you, Ma-cha, Mum. Always.

I really treasure the fact you enjoy being with the kids
and the kids are always saying,

“"I want to go to Ma-cha’s place!”

Please stick around for a while yet, Mum.
Texts on the wall (Plate 13):

Mum often claims, “Cancer is a really terrible disease.

Of course people that suddenly die in an accident one day are also unlucky, but this disease is a death sentence yet you still have to live the remainder of your life.

But I’m happy I’m able to have this last chance to get my affairs in order and spend time with my children and grandchildren before I die.” (Plate 13)
Texts by my Mother on the wall (Plate 14 and 15):

It was a beautiful star-filled night.

I was in labour, holding my swollen belly.
We don’t yet have our own car at the time.

Five, six steps, it’s so far...

Resting every few steps of the long walk to the hospital in the middle of that cold December night with your dear father carrying me under his arm.

There was nothing he could do to ease my suffering, but support me, yet he remained, a trait I resented at the time.

I glanced up at the sky and it was filled with stars.

I don’t know if it was because I had held on until the last moment or not, but after I entered the delivery room it all went smoothly, and you came out quickly.

Perfectly healthy, thank God. An angel with jet black hair.

Married at 20, a baby at 21. Knowing nothing of the world and still a child myself, you made me your mum.

I loved you, oh how I loved you. I held you and played with you all the while you were awake. And I watched you all the while you were sleeping.

Then before I knew it, you, my darling, had become a mother of three...

Every year when your birthday draws close, I remember that star-filled sky in the Tama Hills of Tokyo that December.

3.3 Our Mother–Daughter Relationship amid the Fear of Death

In this section, I examine our mother–daughter relationship amid the fear of my Mother’s impending death. The psychoanalytic Oedipus complex is discussed briefly in relation to my experience of being separated from my Mother. While a psychoanalytic analysis is not the primary concern of this section, a consideration of this condition is
revealed as a formative experience for how this research developed. This is followed by reflections on our mother–daughter relationship after my Mother was diagnosed with cancer.

**Oedipus Complex and My Separation from My Mother**

As Nancy Chodorow (1978) explains, a child forms their identity and personality through their relationship with his/her mother. Because the desire to be assimilated with the mother’s being is never fully satisfied, the child in processes of both bodily and psychical separation from mother comes to see themselves as a separate bodily self—connected to others and yet also separate in mind (the hidden, interior self) and body. In psychoanalytical theory, the infant develops his/her self-love (narcissism) and self-hate (depression), recognising their self and the surrounding world through their relationship with their mother or other primary caregiver of care and identification. This primary love and self-identification affects most people in later life and they keep trying to recreate this primary intimacy often through the fantasy of love expressed in merging with the mother (1978). The mother’s body is this site of an original primary experience of being merged and enveloped in the mother without any sense of bodily separation as another evolving person. Returning to this original existence is one version of love expressed in religious beliefs of returning to God and merging into ‘his’ Oneness. This patriarchal appropriation of the mother in god as father has been a part of feminist religious scholarship and debate. On the other hand, this origin in her body and nurturance places the mother negatively as a symbol of dependence, regression, passivity, and a lack of adaptation to reality. However, the child (in psychoanalysis, the child in the Oedipal story is male) eventually turns their back on their mother to acquire independence, individuation, progress, activity, and to participate in the real world (1978). This separation into independence is highly gendered, with the expectation that girls will remain more attached to their mothers because they share the same gender identity and sexed bodies. Without wishing to go further with this theory, I want to acknowledge this factor, which has a long history in feminist engagement in psychoanalysis such as that found in extended works by Chodorow.
According to Jessica Benjamin (1995), the Oedipus complex, which is based on the Ancient Greek myth of Oedipus and developed by Sigmund Freud (1931), states that a child (figured as male because it is a heterosexual and heterosexist paradigm) is attracted to their mother and the separation process from this primary love leads to the development of their identity as male and therefore not female like their mother. This identity in the negative, through rejection—‘I am not like her, my mother’—is how women are subjected to the male subject as the norm and centre. A boy competing with his physically greater father in fear of castration gives up his mother as a love object (again, the assumption in psychoanalysis is that it is a male heterosexual subject), and so he starts seeking substitutes in society. A girl, however, normally pursues different processes than a boy as she does not have a penis (symbol of power and authority) and has to deal with a complicated individuation from her mother, who is of the same sex (Benjamin 1995).

‘Penis envy’, which was theorised by Freud, postulates that a girl feels castrated (disempowered because symbolised negatively as lacking) and blames her mother for this. It is of course a well-known controversial term in feminist studies; however, many scholars agree that a girl’s Oedipus complex is more intense and insecure than a boy’s as her primary love is with the same sex and is ambivalent (Firestone 1970; Greer 1970; Millett 1970; Friedan 1963). This is not to say that these feminist scholars agree that this should be so, but they recognise that in the symbolic order of patriarchy, women and the feminine occupy a secondary position of power and authority relative to men and the masculine, and are therefore put in the position of having to challenge and subvert this hierarchical order and status. While girls can and do identify with their mothers in this structure of normative gender—becoming like their mothers—boys are supposed to give up this identification (internalise and hide it) and align their gender primarily and more overtly with their father, or the masculine. This means that boys are expected to separate more from their mothers (or appear to do so because internally they might identify more strongly than they are allowed to openly show) and girls can still stay connected as like their mothers. Carl Jung’s (1915) Electra complex (usually given less attention in psychoanalysis) expresses the girl’s murderous relationship to her mother in rivalry for her father’s affections (again, this is heterosexual/heterosexist) but also, just as importantly, as aggression towards the
mother for her lack of power. Daughters can direct anger at their mothers because they come to realise their impotence relative to men in the wider social world.

The figure of the mother is also complex because she occupies both life and death—she gives life through her body but she also at the very same time gives death. The mother then is the origin and source of our own life and mortality—this makes her mortality particularly poignant. When the mother dies, our origin and first home dies too. Whether as a daughter or a son, this is a powerful reality. I now turn to my own childhood in relation to these questions of independence and my relationship to my mother and father.

As a child growing up in Japan, I was not the type to just unquestioningly do what my parents told me to do. Reflecting on this, I was probably more difficult than many of the children around me. I had always been fiercely independent; I was a rebellious child who desperately kept pulling away from my parents, especially from my Mother. In some ways, I did not fit the psychoanalytical model of attachment to the mother as a daughter. However, I think I did have that classic position of blame towards the mother as ‘lacking’—recognising unconsciously her lack of power as a woman in a patriarchal society. While mothers might have emotional power over their children, they do not as women have social power like that of men. The more my parents cared, the more I deliberately withdrew from them. Perhaps I was trying to find my place in the world by rejecting my Mother. I was immature and everything my Mother did provoked me to defy her. I would ignore her and go days without speaking to her. Even when we were out, I would walk as far away from her as possible. This went on for several years until one day, when I was in Year 9 at school, my parents separated. I decided to blame my parents’ divorce squarely on my Mother. Her existence became unforgivable to me. I barely saw her until I became an adult.
In 1989, a little while after my parents’ separation, my Mother immigrated to Australia. I decided to visit her in 1992 as I had started living by myself and was no longer under the control of my Father. From then on, I visited at least once or twice every year and my feelings towards her gradually started to change. I had also grown up. All that time I had wanted to see her, but had not been able to and when I finally did, I found I was no longer able to deny the love I had for her. After permanently moving to Australia in 2001, I was also gradually able to pour out my daughterly grievances to my Mother, who had moved out after the divorce. The strange thing was that the love I had for my Mother, who I had once thought so unforgivable, quietly diffused each grudge as I vented them to her. Ultimately, I had wanted my Mother to listen to my feelings when I was young. I had wanted to talk more with her. Then, before I knew it, I had three children of my own. Now I am painfully aware of how it feels to be a mother.

When I was a child, my ambition for when I grew up was to be different from my Mother. I subconsciously wanted to surpass her and become an even more amazing person. Lately, though, when I look at my ageing self in the mirror, I increasingly think how much I am like my Mother. And now, that is a nice feeling.
Mother–Daughter Relationships amid the Fear of Impending Death

In their psychological research on mothers’ relationships with their children, Lichtman et al. (1985) showed that 54 percent of all mothers they interviewed experienced some change in their relationships with their children after having breast cancer. More frequent and diverse problems were reported in mother–daughter relationships than in mother–son relationships. The research also revealed that more drastic surgery in mothers who were ill, such as a mastectomy, became a problem with sons, but not with daughters. The problems that mothers reported varied depending on the age of their daughters. Young daughters often showed extreme fearfulness. The most dramatic and rejecting responses were reported in a group of adolescent daughters and 4 percent of mothers claimed that their daughters moved out while they were unwell, while no cases of sons leaving home were reported. Some post-adolescent daughters tended to be more distant and avoided discussing the cancer with their mothers. The research suggests that the increased problems with daughters could stem from their own fear of developing breast cancer and the fact that their mothers may lean more heavily on them for support, creating demands (Lichtman et al. 1985). Helen O. Adler (1998) also points out that unconscious assimilation developed with the
mother can cause extreme anxiety in the daughter about the mother and also fear of a similar death. This can result in either disengagement from or bonding with the mother (Adler 1998).

As mentioned earlier, I had conducted research in 2013 on taboos and the denial of death in society by shadowing funeral directors. Through this process, I discovered some negative incidences caused by avoiding the topic of death, and so one of my aims has been to encourage other people to talk more openly about death and dying. Thus, I did not have a problem discussing my Mother’s illness and the future with her. However, I realised how fearful and heartbreaking it is to talk about death when it is an impending reality.

I did not have many issues in my mother–daughter relationship from fear of my own death. But I know how scary it is to face the risk of a similar death and I understand that some people might subsequently start avoiding their ailing mother. In my case, not only my Mother but also my sister has had breast cancer. I had been thinking
about having a mammogram from the moment I turned forty, the age that I became eligible for free screening, but I had put it off for three years. I knew I should do it, but I just could not face it.

I have a very good friend who is also a breast cancer survivor and after listening to her advice, I finally went for a mammogram. They found something in my breast and I had to go back for a biopsy the following week. Strangely, I was not at all scared until I lay down next to the mammogram machine. I suddenly felt my emotional resolve crumble as the nurses started preparing a huge needle-like suction device and connected it to a noisy machine that looked like an industrial-sized vacuum cleaner. I was terrified, and I realised that what I had been feeling could be described as denial until then. When it was all over, my hands were literally shaking, so the nurse held them as she took me to the waiting room and made me a cup of tea. Fortunately, the result from the biopsy was benign.

My Mother found out that she has the BRCA 1 gene a few years ago, which carries a higher risk of cancer. Again, I avoided seeing the recommended gene specialist for a year. After I finally went and found out that I do not carry my Mother’s gene, I cried in front of the specialist. These reflections have revealed to me how much I fear cancer and death, and why the topic of death is important to me as a researcher and creative practitioner.

According to the research conducted by Lichtman et al. (1985), a relatively large number of women reported an improvement in their relationship with their children after they were diagnosed with breast cancer. Some responses revealed an increased sense of closeness and ability to share personal concerns. Among those mothers who experienced any changes with their relationships with children, 72 percent reported that their current relationships with their children were better, overall. Some responses revealed an increased sense of closeness and an ability to share personal concerns (Lichtman et al. 1985).

For Breast Cancer Daughters Tell Their Stories, Julianne S. Oktay conducted research from the daughters’ points of view. She observes that “daughters of women who

---

BreastScreen Queensland operates a screening program specifically designed to target women aged fifty to seventy-four years; however, they also accept women in their forties or seventy-five years and older for free screenings (BreastScreen Queensland 2017).
survive breast cancer often express worry about their mothers, a feeling that would not normally be common at their stage of life” (Oktay 2005, 256). Many daughters whose mothers have survived breast cancer feel very close to their mothers—“58 percent of these women indicated on the final questionnaire that the breast cancer made them feel closer to their mothers” (Oktay 2005, 258), which Oktay claims may arise from their recognition of their mother’s vulnerability. Daughters also respect their mothers more as they see their mother’s endurance during her illness. Ninety-two percent of the daughters checked this category, and some showed extreme concern for their mothers. Some daughters changed their priorities in life. For example, in Oktay’s case studies, one woman became a breast cancer advocate and is now studying to be a nurse. Another woman put more emphasis on her family as she had learned the importance of family in her life. Regardless of age, daughters’ responsibilities increased during their mothers’ illness, and daughters who were the eldest in their families had greater responsibilities. Their relationship with their mothers also became more mature during their mothers’ illness. Oktay also points out that “The effect on a daughter may be minimal if the family has had no prior problems; open communication exists; the daughter has an older sister; the cancer was caught early; or the mother had limited treatment and no recurrence” (Oktay 2005, 261).
In my case, the relationship between my Mother and me has changed, becoming closer and more intimate. Both of us used to dislike talking over the phone. However, my Mother now calls me at least once a week and we enjoy chatting about insignificant things such as what she bought when she went shopping the day before and how she enjoyed watching a Japanese TV show on the Internet. We also see each other more often. I take her to her doctors’ appointments, we have lunch together, and we enjoy going shopping together.

The primary interaction between a mother and a child involves bodily experience, as Adler (1998) highlights. A mother feeds, bathes, and holds her baby with full physical contact. Adler found from her case studies that the nursing of aged mothers by their daughters represents a second chance for bodily interaction between them: “This extended period of intimacy provided an opportunity to renew and finally master previously unresolved struggles around attachment and separation” (Adler 1998, 331).
When my Mother had to undergo cataract surgery a few years ago, I took my Mother to her appointment with an eye specialist. I had to hold her hand as we walked across the street, because of the results of the surgery. My Mother held my hand very tight and looked at me with a big grin and said, “It is not bad having a health problem at all if we can hold hands like this again!” I could not even remember when we last held hands. I assume it would have been sometime around my first day of school.

When a mother becomes weak and ill, her daughter has to ‘mother’ her own mother and the roles are reversed. The fear of being manipulated by her mother disappears and the mother becomes the dependent. The terminal illness makes the daughter realise that their time together is limited, creating an urgency to spend as much time with the mother as she can (Adler 1998). Guilt from Oedipal-based feelings, which defensively devalue the mother, can also cause the daughter to change into a very
loving and determined carer. The daughter begins adoring and idealising her mother just as she used to in her early childhood (Adler 1998; Oktay 2005; Fischer 1986).

My Mother claims, “Getting a cancer sentence is cruel. No doubt about it. But for people diagnosed with cancer, perhaps they have also been given a last chance at life. Now I have some time to prepare before I go.” This experience has shown me that the last chance at life is granted only to someone who has had the crushing experience of being confronted with their own death.

As the daughter of a mother diagnosed with last stage of cancer, I have been given the lucky or unlucky chance to think about my Mother’s death and the remaining time I have with her. Sooner or later, everyone dies. If I am going to have to accept the fact that my Mother will one day die, then, until that time comes, I want to be grateful for being given the chance to spend that time with her, with as few regrets as possible.
When my Mother left home, I was fifteen. I felt it was very sudden and unfair. I was confused and devastated. All I could do was get angry at my Mother. Now I have a chance to rebuild our intimate mother–daughter relationship together. I am now facing our second and final separation, although this time I have been given an opportunity to prepare for it. This doctoral research is based on this realisation. And, while the results are intensely personal, the relationship change that is activated by impending death is likely to be felt in similar ways across cultures.


Plate 26. Yoko Lance *Jacarandas* (from the ‘Not So Soon’ series) 2017
3.4 Between Two Cultures: Group Exhibition *Erehwon*

My Mother moved to Australia in 1989 and after coming to see her regularly, I decided to permanently migrate here in 2001. Both my Mother and I rarely go back to Japan as all our family, including my sister, brother and father, now live here. Living with the Australian culture and mindset has become the norm for us, although we still have some core Japanese perspectives that we value.

However, I often encounter stereotypical Japanese/Australian perspectives and I feel that I do not belong anywhere in this context. I am literally and legally Australian as my citizenship was granted here a long time ago, but people often still see me as Japanese. Conversely, the Japanese also do not accept me as one of them because the Japanese government does not allow dual citizenship. I do not follow Japanese traditions and values much anymore, nor do I know what Japan is like nowadays. The last time I visited Japan was in 2005.

Both my Mother and I have created our own views, blending different aspects of Australian and Japanese perspectives, so I often feel that the only place I truly belong is with my Mother.

When the opportunity arose to participate in a group exhibition with seven other artists of Asian background in Brisbane in January 2017, I chose to focus on two areas: my state of limbo and sense of “belonging nowhere”; and eating as an act of living in light of the impending death of my Mother. The introduction of the act of eating to my practice has developed as my relationship with my Mother develops. Every time I see my Mother, we eat some Japanese food together. Sometimes she cooks and sometimes we go to Japanese restaurants. However, the Japanese cuisine in Australia is not authentic, as most of the ingredients are sourced in Australia. They are very similar, but slightly different. The rice is often medium grain instead of short; the pumpkin is rather soggy instead of soft and fluffy when boiled in soy sauce and mirin to make Nimono; the cucumber is too big for pickling with salt and vinegar to create Sunomono; and the skin of the eggplant is too thick and hard for deep frying then soaking in broth to make Agebitashi. Many Japanese restaurants cater to locals by over accentuating the interior design so that the Australian clientele feel it is authentic Japanese, instead of adopting the genuine contemporary Japanese style similar to the West.
My Mother and I live in this context and state of limbo. However, I have never felt overwhelmed because I have always had my Mother close to me. The curator of the exhibition *Erewhon: from nowhere to now here*, Donal Fitzpatrick, stated in the accompanying catalogue:

> With reference to Samuel Butler’s book *Erewhon* (1872) and its particular influence on Gilles Deleuze’s construction of ‘nomadism’ (1986) and his concept of ‘difference’, the title of this exhibition was a reworked spelling of the reversed word ‘nowhere’, that evokes both the passage from the distributed, migrated space of the refugee / traveller and the imaginary, transformed and always multiple reception at the site of destination/arrival. (Fitzpatrick et al. 2017)

As Deleuze suggests, my Mother and I have created a unique space together, embracing both cultures and perspectives where we too can truly belong.

*Erewhon: from nowhere to now here* was held at the Pop Gallery in Brisbane in January 2017, and featured eight artists: Sara Irannejad, Piyali Ghosh, Doyoung Lee, Vanghoua Anthony Vue, Thirawut Bunyasakseri, Tingting Li, Sha Sarwari and myself. *Erewhon* was presented to the public, embracing, restating and questioning our multicultural community, and reflected my own state of feeling in limbo.

*Plates 27. Yoko Lance Erewhon 01 2016*
Plates 28. Yoko Lance Erehwon 02 2016

Figure 27. Donal Fitzpatrick et al. Erehwon Online Exhibition Catalogue 2017

https://issuu.com/yokolance/docs/erehwon
Conclusion

The project *Not So Soon* (2014–2018) consists of a series of photographic and video pieces compiled from photographs and interviews with my mother; a diary exchange between my mother and I; exhibitions; and this exegesis. The research investigates how a terminally ill mother and a daughter comprehend the mother’s impending death, and how the mother–daughter relationship, amidst the process of dying, can be presented to a public who often withdraw from discussion of the topic. Based on an autoethnographic approach with cultural analysis and interpretation, the final outcomes of this research contribute to new ways of perceiving death and dying in modern day, multicultural Australia. This research methodology was employed to better understand a dying person’s state and his/her familial relationships in a particular context. The research has transitioned from investigations into a broader overview of death denial toward a personal, relational experience of impending death. Through this process, I have discovered, as others might, that familial bonds can strengthen in times of crisis. Moreover, in sharing this work publicly, the research has revealed a collective empathy and general fear of death and dying. Photography unveils personal moments to the public. The images of this research revealed a dying mother, her perspectives and familial relationships, and invoked questions about how we might face our own mortality. One aim in sharing this personal story of love, tension and fear in the moment of crisis is to hold up a mirror to society, so that others might reflect upon their death and dying, as well as those of their family. My photographic approach was intentionally intimate but not overly emotive. I sought an affective space where individual emotions can be revealed and reflected upon, rather than forcing one perspective of this life event. Further, the research outcomes operate as an antidote to the kind of pornography of death that Gorer (1955) theorised, and which was later explored at length by Sawai (1991), who notes its desensitising and dehumanising effects. While I share similar strategies to selected artists analysed in Chapter 2, my research uniquely contributes to discourses of death and dying in that I sought a revitalised bond through the experience of impending death, one that necessarily has to transcend cultural and generational differences. In doing so, I join those few practitioners—surveyed in this is exegesis—who successfully and rigorously
combine academic research with strong visual outcomes to expand discourses on death and dying.

In many societies, including Japan and Australia, death is often a taboo subject that people avoid talking about. The decline of religious influence and the rise of individualism in the twentieth century have contributed to this evasion, particularly as institutional death becomes more common. This reality steers people away from the opportunity to become involved with the burdens that follow a death. Yet, at the same time, there is a proliferation of images of death on the news, in dramas, and in games that use, as Sawai (1991) has described, death as information and death as pornography. We are simultaneously confronted with and shielded from death (Walter 1991; Sawai 2005). Although my Honours research (Lance 2013a; Lance 2013b), a documentary research project where I followed funeral directors in the South East Queensland region, showed that over the years the topic of death has gradually been emerging from the shadows and re-entering the public conversation, a fear of death still prevails, leading to a denial of death in society. In Japan, some unique perspectives regarding death and dying have developed. In my analysis of Mika Ninagawa’s The Days Were Beautiful (2017), I provided evidence of Japan’s unique approach to representations of death and dying. My doctoral research project Not So Soon is created in this context, displaying multi-cultural attitudes through my experience as a Japanese-Australian woman.

Despite the work of Elisabeth Kübler-Ross (1970) attracting some controversy, I have adopted her effective ethnographic approach as a storyteller to learn from dying people. I purposefully decided on autoethnography, utilising photography and video interviews to conduct my research. These methods of representation were carefully considered due to their close metaphysical relationship to death, as posited by Susan Sontag (1977), Roland Barthes (1980) and Geoffrey Batchen (2004). As Sontag (1977) states, all photographs are a form of memento mori, and she likens taking a photograph to capturing the moment of death. Photography is a method traditionally used in research disciplines such as anthropology, ethnography, and sociology, including recent fields such as visual sociology and visual ethnography. I share Patricia Leavy’s understanding that the creative arts can serve, refine, and expand the work of
other qualitative research in the social sciences (2009). This research project has embraced Heewon Chang’s notion of autoethnography which, as he states, requires cultural analysis and interpretation with narrative details (Chang 2008). As Bochner and Ellis further explain (2003), artful autoethnography can create broader discussion and give rise to questions rather than offering closed conclusions or statements. It concentrates on self-narrative for self-understanding and provides a window through which to understand others. Therefore, this research contributes to discourses of death and dying through visual representation via the personal narrative of a dying mother.

As Allan Kellehear (Kellehear 2007) states, death motivates and activates people. Throughout art history, the subject of death has motivated many artists, giving rise to whole genres such as vanitas or memento mori. However, it has not lost its appeal for contemporary artists. Mami Sunada (2011), Walter Schels and Beate Lakotta (2008b), Sophie Calle (2013), Briony Campbell (2009), Phillip Toledano (2010) and William Yang (1996) captured the death of their loved ones, sharing the reality of death in a calm manner in an attempt to reach beyond curiosity, melancholy, shock, fear or agony.

Individual interpersonal factors and personal resources largely affect our fear of death, therefore I examined my mother’s fear by applying two psychological fear of death scales: the Reasons for Death Fear Scale (RDFS) (Abdel-Khalek 2002) and the Collet-Lester Fear of Death Scale (CLFD) (Lester and Abdel-Khalek 2003). These interviews were transformed into a video in 2015 and it suggests that people can accept the brutal facts of death and dying when they face it in reality. The project revealed that my mother’s fear of pain persists even though my Mother has already accepted her mortality. However, some fear may still persist until the end of life. Thus, denial of death cannot be totally eliminated.

The fear of a mother’s impending death also affects a mother–daughter relationship, as Adler points out (1998). My second project, the diary exchange in Japanese blog format, was developed to reflect the thoughts my Mother and I had on this experience. The aim of this was to record and discuss our mother–daughter relationship amid the fear of my Mother’s approaching death. I examined the Oedipal
conflict between us in the past and the shift towards our current, close relationship. The project suggests that a mother–daughter relationship can change in a positive way, despite the mother’s impending death. The mother–daughter relationship, while often captured powerfully and truthfully in social science theory and psychoanalysis, also goes beyond, and slips through, these representations. The transitions that occur in the course of our lives can reveal significant, unpredictable changes in the familial relationships. It is very unfortunate to be diagnosed with a terminal illness, but this research invites people to consider the situation as if they have been granted the time to treasure their last moments together.

This research has caused me to reflect on my research trajectory over the last few years. During my previous project about funeral directors and the denial of death in society, I discovered a need to talk about death more openly. My interviews with my Mother using the fear of death scales applied this knowledge, revealing her fear of physical pain and the loss of her beauty in the course of death. For Kübler-Ross, “death itself is not the problem, but dying is feared because of the accompanying sense of hopelessness, helplessness, and isolation” (Kübler-Ross 1970, 268). This research, then, supports the idea that we should not pressure anyone to stop denying death and dying; however, in order to understand and accept those who are struggling with their fear of death, we need to be aware that we are in denial about death, and to consider the reasons why this denial is present. This knowledge enables us to talk in a calm manner about death and to support people when they are ready to open up about their fears in relation to it.

Most importantly, this research is a call to accept terminally ill people as they are, as they choose to express their experience of death and dying. Photographic representations of death and dying can aid this process, displaying a photographer’s perspective as if a window, allowing the audience to explore and reflect on their own position. Not So Soon contributes to the field in which photographic representations of death and dying asks us to recognise our own vulnerability while considering the vulnerability of others.

Terminally ill patients are often expected to show a positive attitude when reflecting on their own fear and denial of death, and this issue will be investigated further in my future research as well as issues related to a ‘good death’ and well-managed dying. In
future research, also I aim to extend upon notions of intersectionality, which I identify as a discourse that will enable me to engage with suppressed or unheard voices of female Asian immigrants facing death and dying. Publishing a book is another goal, as it will allow me to reach broader audiences.

This research champions the fact that the voices of terminally ill patients, and their family, should be given more attentions in order to understand them better. Throughout the course of this doctoral research project, I have witnessed people open up about their own experiences of death and grief. I recognise these suppressed stories and emotions as needing a place for expression. We sometimes need to deny death in order to survive today. This attitude is understandable, and it should be accepted. Therefore, research such as this encourages understanding and open dialogue. One certain fact of life is that death is inevitable. Sooner or later, we must all face the death of others, our loved ones, and ourselves. Death is brutal and fearful. But life is beautiful, and we can embrace it until the last moment.
Appendix 1: Ethics information

Not So Soon: a case study of a mother–daughter relationship amid the fear of the mother’s impending death

INFORMATION SHEET

Who is conducting the research

The researcher, Yoko Lance
Doctor of Visual Art candidate, Queensland College of Art, Griffith University
Ph: 0402 055 884
Email: info@yokolance.com.au

Supervisor, Dr Laini Burton
Queensland College of Art, Griffith University
Ph: (07)555 27121
Email: l.burton@griffith.edu.au

Why is the research being conducted?

Some research, such as *The Loneliness of Dying* by Philippe Elias (1982) and *On Death and Dying* by Elisabeth Kübler-Ross (1973) indicates that terminal ills often experience that people around them change their attitude towards the dying person. Many people struggle how to communicate with terminal ills because they do not know how to react with death and dying, and this sometimes leads to change their relationships. Denial of death in society leads a topic of death as taboo and makes people hard to speak out. Therefore, this research aims to investigate case studies of terminal ills, their life and experience in these contexts.

The researcher and a Doctor of Visual Arts candidate of Griffith University, Yoko Lance will conduct a social documentary research project utilising still photography and HDSLR video interviews under the supervision of Doctor Laini Burton of the Queensland college of Art Gold Coast, Griffith University. This qualitative research will investigate the potential stigma of terminal ills and how they communicate with others as well as their mother–daughter relationship.

What you will be asked to do

The photographic documentary research will be conducted by still photography and HDSLR videos including video interviews. The researcher will document her terminally ill mother and people around them. Some participants might be asked to let the researcher documenting their personal life as well. People around the mother such as family members, friends and medical workers might be included in this research, but strictly upon a prior agreement. Some participants might be asked to attend photography shootings in the studio as well.

The basis by which participants will be selected or screened

93
The mother of the researcher is selected for this qualitative research as a main participant. People around the mother, such as friends, family members and medical workers will be asked to be in the frame of photography/videos upon prior agreement.

**The expected benefits of the research**

Showing the life and voices of terminal ill will benefit various people who work in the medical industry, family and friends who have terminal ills around them, and also the terminal ills themselves. It can also increase the public awareness regarding burden and the potential stigma of terminal ills.

**Risks to you**

You might be asked some personal questions, but you do not have to answer every question and your reply to questioning is voluntary. The researcher understands the sensitivity of the subject matter, and will not approach people around the terminal ill unless introduced.

**Your confidentiality**

Your images and personal information will be exposed in public on the publications, online contents or exhibitions if you are willing to participate. The consent form will be provided for you to sign; however, you can change your mind and withdraw from the project anytime. All the images will be shown to you before the publication, online contents or exhibitions to make sure that you are happy with the final work. All the collected data and images will be kept and published as the work of Yoko Lance, and may include the researcher’s own comments.

**Your participation is voluntary**

Your participation in answering the questions and being exposed in still photography / videos is voluntary. You can change your mind and withdraw from this research anytime. You can also tell the researcher whenever you are not willing to reveal any part of your work / personal information. You can also choose to use a nick name instead of revealing your real name.

**Questions / further information**

Please feel free to contact the researcher, Yoko Lance for any further information. You can also contact the supervisor of this research project, Doctor Laini Burton any time.

The researcher, Yoko Lance  
Doctor of Visual Arts candidate, Queensland College of Art, Griffith University  
Ph: 0402 055 884  
Email: info@yokolance.com.au

Supervisor, Doctor Laini Burton  
Queensland College of Art, Griffith University  
Ph: (07)555 27121  
Email: l.burton@griffith.edu.au

**The ethical conduct of this research**

Griffith University conducts research in accordance with the *National Statement on Ethical Conduct in Human Research*. If you have any concerns or complaints about the ethical conduct of the research project, please contact the Manager, Research Ethics on 3735 2069 or research-ethics@griffith.edu.au.

**Feedback to you**
The researcher will show you the final work before the publication and exhibition to make sure that you are happy with the final work. You will be informed about the exhibition or publication details.

Privacy Statement

As part of the University's policy the following paragraph must be included:

*The conduct of this research involves the collection, access and/or use of your identified personal information. As outlined elsewhere in this information sheet, your identified personal information may be included in exhibitions, publications and online content. Other than this disclosure, the information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the Manager, Research Ethics on 3735 2069 or research-ethics@griffith.edu.au.*
Not So Soon: a case study of a mother–daughter relationship amid the fear of the mother’s impending death

Research conducted by Yoko Lance,
Doctor of Visual Arts candidate at Queensland College of Art, Griffith University
Supervised by Dr Laini Burton, Dr Heather Faulkner and Dr Margaret Gibson
Email: info@yokolance.com.au; l.burton@griffith.edu.au
Ph: 0402 055 884 (Yoko Lance), (07) 555 27121 (Laini Burton)

CONSENT FORM

Participant Details

Name: 
Address: 
Phone: 

I, ____________________________________________ (name) of ____________________________________________________________
________________________________________________________________________________________________________
________________________________________________________________________________________________________
Understand that:
☐ I do not have to participate in this project if I do not want to
☐ If I agree to participate I can change my decision and withdraw from the project at any time. I do not have
to give a reason for withdrawing from the project and that there will be no penalty for doing so
☐ There is no payment for my involvement in this project
☐ The information I give to Yoko Lance may be published at some time in the future
☐ if I have any concerns about the conduct of the people involved in the project I can contact the
Manager of Research Ethics at Griffith University
☐ I will be asked for additional consent for any use of the information I have provided outside the
requirements of Doctor of Visual Art Candidature for Yoko Lance

Give my permission for Yoko Lance to:
(tick the box next to those activities you will participate in)
☐ Interview me
☐ Photograph me
☐ Record our conversations with videos or sound recording equipment
☐ Use the photographs, video, sound and words in future exhibitions
☐ Use the photographs, video, sound and words in publication form
☐ Use my name whenever the work is shown

.................................................................................. (signature)
.................................................................................. (date)
Some additional information:

The intention of this project is to tell the stories about the life of terminal ill and her mother–daughter relationship to the broader community. This story will be edited and arranged by the author, Yoko Lance, and may include her comments. All the information you give to Yoko Lance will be available for publication. It is hoped that by your participation, this social documentary research will engage the Australian public in dialogue, establish a research foundation of recorded experiences from which further discovery can take place.

The stories you tell will be made into academic paper as well as exhibitions and will be shown in galleries, websites, books, online publications etc. The exhibitions and publications will be accepted as the work of Yoko Lance. If you tick all the boxes above, your image and name may be published in the publications and exhibitions. The research paper, still photographs and multimedia contents will be available for public access, and there is no particular limitation for the duration.

As part of the University’s policy the following paragraph must be included:

The conduct of this research involves the collection, access an/or use of your identified personal information. As outlined elsewhere in this information sheet, your identified personal information may be included in exhibitions and publications. Other than this disclosure, the information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan at www.griffith.edu.au/ua/aa/vc/pp or telephone (07) 3735 2069.

The paragraph safeguards your privacy. It means that I will only use your information in the ways we have agreed upon. The only exception to this is when we are required by law to do so or if we contact you and get your permission.

If you have any questions, please feel free to ask. If you have any more questions later, I will be happy to answer them. You can contact me on the phone number above or call Griffith University (number above) and ask for myself. If you have any concerns with the way the project has been carried out you can contact Manager, Research Ethics at Griffith University on 373 52069 or research-ethics@griffith.edu.au.
Appendix 2: The Reasons for Death Fear Scale
(Abdel-Khalek 2002)

Many people fear death for a variety of reasons. Here are some statements which indicate such causes. Please read each statement carefully and circle the choice which best expresses your opinion on the scale shown, starting with strongly disagree (1) to strongly agree (5).

<table removed due to copyright restrictions>
Appendix 3: The Collet-Lester Fear of Death Scale Version 3.0
(Lester and Abdel-Khalek 2003)

How disturbed or made anxious are you by the following aspects of death and dying? Read each item and answer it quickly. Don’t spend too much time thinking about your response. We want your first impression of how you think right now. Circle the number that best represents your feeling.

<table removed due to copyright restrictions>

__________________________________________________________________________________

Scoring: The circled scores are summed for each 7-item subscale.
Appendix 4: Questionnaires for interviewing my Mother

List of questions and answers from questionnaires given to my Mother, Masako Katayama (all translated into Japanese by the researcher as follows):

How disturbed or anxious are you by the following aspects of death and dying? Read each item and answer it quickly. Don’t spend too much time thinking about your response. I want your first impression of how you think right now. Select the number that best represents your feeling. (1: Not at all – 5: Very)

死と自分が死ぬことにについてどんなことに恐れ、心配だと感じますか？
あまり時間をかけずに第一印象で思いついたまま 1～5 で答えてください。
（1 = あまり心配していない、怖くない 5 = 心配だ、大変怖い）

The Reasons for Death Fear (RDFS) questions and my Mother’s answer

1）Fear of heavenly punishment: 3
   天罰が下るのは怖いと思う？

2）Worrying about one’s offspring: 5
   子供たちのことが心配？

3）Too many sins: 1
   罪深すぎるから

4）Losing life that teems with meaningful things: 1
   人生は意味深いから

5）Parting from relatives and loved ones: 2
   家族や親戚、大切な人たちと別れるのは嫌だから

6）Leaving behind secular pleasures: 2
   現世での喜びや楽しみを置いたまま去ることになるから

7）Fear of hell and doomsday: 2
   地獄や最後の審判への恐怖

8）The terribly strenuous moment when the soul parts from the body: 1
   魂が肉体から離れるときに、相当な努力が必要だと思うから

9）Failure to perform religious duties and obligations: 1
   宗教的な義務や責任を果たせないから

100
10) Death entails so many vague and unknown issues: 1
死には曖昧で未知なことが多い

11) The element of surprise in death: 1
死の意外な要素

12) Lack of faith: 1
信仰心が足りないこと

13) The grieving of loved ones: 5
愛する人たちが嘆き悲しむこと

14) Torture of the grave: 1
墓場に入ることは拷問のようなだ

15) Acute pains associated with dying: 5
死ぬときには激しい痛みをともなうこと

16) Grieving over what one will leave behind, e.g. wealth, valuables, etc.: 1
残されるものに名残りおしさを感じる（富、価値のあるものなど）

17) Loss of self or identity: 4
自分自身が無になること、自己がなくなること

18) Death puts an end to one’s plans and objectives: 1
計画や目標がそこで終わりになってしまうこと

The Collet-Lester Fear of Death Scale Version 3.0 (CLFD) questions and my Mother's answer

Your Own Death

1) The total isolation of death: 1
亡くなると完全に世界から切り離されてしまう

2) The shortness of life: 1
短い人生

3) Missing out on so much after you die: 1
亡くなったあとに起こるいろいろな機会を逃してしまうこと

4) Dying young: 1
若くして亡くなること
5) How it will feel to be dead: 1
死ぬとどんな風に感じるのか

6) Never thinking or experiencing anything again: 1
もう何も考えられなくなうこと、またはもう何も経験できなくなること

7) The disintegration of your body after you die: 1
亡くなると肉体がなくなること

Your Own Dying

8) The physical degeneration involved: 4
肉体が老いていくこと

9) The pain involved in dying: 4
死ぬときに痛みを感じること

10) The intellectual degeneration of old age: 3
年老いて知能が落ちていくこと

11) That your abilities will be limited as you lay dying: 5
死へ向かって横たわるときには、できないことばかりになること

12) The uncertainty as to how bravely you will face the process of dying: 1
死のプロセスが目前に迫ってきたときにどれだけ勇気を持っていられるかわからないこと

13) Your lack of control over the process of dying: 1
死のプロセスは自分がコントロールすることができないこと

14) The possibility of dying in a hospital away from friends and family: 1
病院で、家族や友人から離れて亡くなる可能性があること
Appendix 5: Interview with Masako: whole original transcript in Japanese

Questionnaire: RDFS

Video: 1586.mov

1) Fear of heavenly punishment
天罰が下るのは怖いと思う？

怖いというより、仕方がないなって思う。で、できるだけ、受けないようにしたいなと思いますね。

Video: 1587.mov

2) Worry about one’s offspring
子供たちのことが心配？

とても、やっぱり心配ですね。

3) Too many sins
罪深すぎるから

とても罪深いと思いますね。死ぬときには、心配じゃない。1です。だってしょうがないでしょう、今さら。

Video: 1588.mov

4) Life teems with meaningful things
人生は意味深いから

基本的に、死ぬのが怖くないのです。意味深いとは思いますね。だから意味深いと思うことに対しては段階では5、死ぬときにうんぬんに関しては1。

なんだけど、答えになってるかどうかわかりません。

Video: 1589.mov

5) Parting from the relatives and beloved
家族や親戚、大切な人たちと別れるのは嫌だから

いつかは、必ず分かれる時が来るわけだから、それに対してはいくら心配してもしょうがないし、もうちょっと待って言ってどうにでもならない。だから、しょうがないな。いつか来る。明日かもしれない。百年先かもしれないという感じです。
6) Leaving behind secular pleasures
現世での喜びや楽しみを置いていきなりのことになるから

2

この世にいろんなもの置いていくのはしょうがないよね。棺おけの中に持ってけるわけがないから。もう、これはすべてしょうがないね。そのときは来たら、置いていくものは置いていく。

7) Fear of hell and doomsday
地獄や最後の審判への恐怖

2

天国とか地獄とか何かはあると思うけど、どこ行かされるかわからないよね。そのときになるまでもね。だからそれは、怖いだったってしょうがないよね。だから、それが恥から死にたくないからとか、天国行きたいだからどうのこうのとかはいない。もう、しょうがない。仰せのままにっていう感じかな。

8) The terribly-strenuous moment when the soul parts from the body
魂が肉体から離れるときに、相当な努力が必要だと思うから

1

昔、私は何度もこのへんから自分が寝てる姿を見たことがあるのね。それで、ただの夢かもしないし、いわゆる幽体離脱ってやつかもしれない。わかんないけれども、抜けるときはすっと抜けるんだと思う。苦しがって出してくれっていうもんじゃないと思いますね。だから、すっと抜けちゃうと思っています。

9) Failure to perform religious duties and obligations
宗教的な義務や責任を果たせないから

0

えー宗教的に。基本的に無宗教ともいえるかもしれないけど、すべての宗教を受け入れるともいえる。これは日本人の特徴かもしれないけど、まったく神様を信じていないわけではない。でもその神様っていうのが仏様であったり、お日様であったり、ただのそのへんの草花であったりというのです。だから、まあ、なるべくね。その、怒らせないように、叱られないようにしたいと思いますね。いわゆる八百万の神々にそむくようなことはしたくないなとは思っています。

10) Death entails so many vague and unknown issues
死には曖昧で未知なことが多い

0
やっぱり、生まれたときからいつか死ぬことが決まってるわけだから。そうですね、理不尽に死ぬのはやっぱり嫌で、嫌ですねやっぱり。理不尽な事故にあうとか、それはやっぱり嫌だと思うけれども。ある生まれたときにすでに運命というものがあって、寿命が決まっているとしたらその日が来たら、「あ、来ちゃったんだな」と受け入れるしかないと思っています。

Video: 1595.mov

11) The element of surprise in death
死の意外な要素

いろんなことに関して、例えば死に関して、あの、確かに怖いっちゃ怖いけれども。今、この年に、この現状で……昔は知らない。十年前は違うかもしれない。でも今この段階では、基本的に死ぬということに対して、えー、恐怖は何もなって言うのが本当ですね。だから、サプライズあるなら、ウェルカムです。

Video: 1596.mov

12) Lack of faith
信仰心が足りないこと

信仰っていうのは、国によってそれぞれやり方が違うと思う。やっぱり日本人っていうのは独特。で、仏教家や宗教家は別として、一般人はほとんどどんな神様も仏様も受け入れてしまうというところがある。だから、信心が足らなくて、一般人はあまり思ってないと思う。特に私は思ってない。自分が信心深いとも思ってない。そんなもんでいいんじゃないかって思っていますね。しょうがない。

Video: 1597.mov

13) The grieving of loved ones
愛する人たちが嘆き悲しむこと

別れの日が来たとき。やっぱり、行く人はね、もうそれでお終い。まぁ先で何か思ってるのかなんかは分からない。でも残されたものは、やっぱり、どんな理由があってね。やっぱり残されたものは辛いよね。だから、そういう辛い思いをさせるのは、申し訳ない、と思う。だからそれが怖いか、死ぬことが怖いっていうことは別ものなのね。ただ、ごめんね一だって言うのが、気持ちですね。だから怖いんじゃない。でも、ごめん。

Video: 1598.mov

14) Torture of the grave
墓場に入ることは拷問のようだ

お墓に関しては、基本的に特にこのオーストラリアに来てからは、お墓はいらないと思っていまずから、まぁ入るのが怖いからいらないんじゃなくて、そういう問題じゃなくて、まぁいらないんだけども。
えー。うーん。生きたまま入れられるのは怖いよね。でも、死んじゃってからは、怖いも何も
ないですよ。

Video: 1599.mov

15) Acute pains associated with dying
死ぬときには激しい痛みをともなうこと

えー。痛みだけは勘弁してください。痛みだけは怖いです。痛みはとってください。お願いし
ます。

苦しむのだけは許して。苦しむのは、5 秒くらいならしょうがないけど。

Video: 1560.mov

16) Grieving over what one will leave behind, e.g. wealth, valuables, etc.
残されるものに名残りおしさを感じる（富、価値のあるものなど）

富に関しては１家族に関しては５だけど。

えー。自分が、残していくもの。ようするにお金とかものとか。そういうものに関しては、持
ってけるわけではない。えー、ま、どうぞ、ご自由に処分ください。まったく未練はないでし
ね。0ですね。

Video: 1561.mov

17) Loss of self or identity
自分自身が無になること、自己がなくなること

えー。ある日突然、何かの事故で死んでしまうということに関しては、怖いというより、困っ
たなっていう感じ。それは、残されるもの。つまり家族に関して、えー、迷惑かけちゃう。自分
に関してはいつ何時、事故でもなんでもいいわけ。そこで、終わってしまうわけだから。
だけどその処理っていうか、あとに残った人たちがいろんな処理をしなければならない。それ
に対しては申し訳ないっていうかごめんなって感じでしょう。だから、やっぱり事故は嫌で
すね。ただ、例えば、保証金がうーんと入ってくるというならば、それはもう、子どもたち
にしっかり渡してあげてくださいねっていう感じはします。

自分自身が無くなってしまうということに対しては、うーん。怖くないっていうかしょうがない
ですね。もうそういうのはめになったっちゃった。それもまた、運命かな。時が来たのかって感
じですね。

18) Death puts an end to one’s plans and objectives
計画や目標がそこで終わりになってしまったこと

今は１。

5 年前なら、やりたいこともいっぱいあったし、それが途中でぶつんと断ち切られるのはとても
残念だったと思う。ただ、今は、やりたいこともないというよりもね。いろいろもう、やっ
ちゃった。やらせてもらった。だからない。で、これから先も、何か新しいことが見つかると
ても今の段階ではもう思えない。だから、それに関しての恐怖というか嫌だなっていうのはもう
ない。いつでもいい。明日でもいい。
Questionnaire: CLFD

Video: 1603.mov

1) The total isolation of death
亡くなると完全に世界から切り離されてしまう

死んでもると、この世との関わりが切れてしまうのか、それともどこかこの辺でふわふわしていていつも見ていただけるのか、これからは誰だか死んでみないとわからない。だからそれに関しては怖いとかそういうものじゃないですね。逆に、見てみたい。このへんでふわふわして、みんなのことを見てたい、とは思います。

Video: 1604.mov

2) The shortness of life
短い人生

人生の長さっていうのって、長いからいいってもんじゃないし、短いからだめってものじゃない。その人の人によって、それぞれ違うと思う。で、私に関しては、もう、十分。もういいわ、ありがとうって感じ。だから、もし明日何かあるとしても短かったなぁとは思わない。長かったとも思わない。そこそこ、ちょうどいいんじゃないっていう感じです。

Video: 1605.mov

3) Missing out on so much after you die
亡くなったあとに起こるいろいろな機会を逃してしまうこと

自分が亡くなったあとに、まだもっといいことがあったかもしれないとか、思ってもしょうがない。亡くなっちゃう、死んじゃうんだから、そこでおしまい。もしできることなら、周りのいろんなことを、上から見ることができたらいいな、とは思いますね。でも、まだまだこれから先もっと楽しいことがあったかもしれないと思っても、それはまったく意味がないと思いますね。

Video: 1606.mov

4) Dying young
若くして亡くなること

ほかの人にに関しては５だけど、自分に関しては１ですね。

今の私が、若いかどうかよくわかりませんね。でも一応若い方には、もし何かあったとき、若い方にはなるかもしれませんね。でも、私自身としては、若くない、十分、ちょうどいいと思ってますね。何かあっても、だからそれに関しては、まったく考えてない。気にしてない。ただ、一つ、長すぎるのは怖い。嫌。だから、ほどほどに、が願いです。

Video: 1607.mov

107
5) How it will feel to be dead

死ぬとどんな風に感じるのか

死ぬとどういう風に感じるかって、死んでみなきゃわからないよね。もうでも、感じられないから死ぬってことなんじゃないかな。感じられなくなるってことが、死ぬってことじゃないのかな。だから、心配してもしょうがない。それが死ぬってことだ。

Video: 1608.mov

6) Never thinking or experiencing anything again

もう何も考えられなくなること、またはもう何も経験できなくなること

死んじゃったら、もう何も考えられなくなる。何もできなくなる。そりゃそうだよね、死んじゃうんだから。でも何度も言うけど、今の私は、まったく気にしてない。で、未練もあるわね。例えば子どもたちのこと。だけど、それ以外のことに関しては、もう十分遊ばせてもらったと思っています。

Video: 1609.mov

7) The disintegration of your body after you die

亡くなると肉体がなくなること

肉体がなくなるということに関しては、それが死ぬということなんだろうし、また死んでも肉体が残ってるって怖いよね、逆にね。だから、この肉体がなくなるとすれば、しょうがないじゃない。

Video: 1611.mov

8) The physical degeneration involved

肉体が老いていくこと

特に最近、体力の衰えを感じたり、いろんな見た目も衰えていくのをはっきりと実感できるようになってくる。やっぱり、嫌ですからね。見たくない、自分では、だからなるべく……あ、ひとまとめのね、例えばとってもしわがあるとか百歳までお元気でいらっしゃる、そういうのにはすごいなぁと思って、それは逆に美しいと思います。だけど、私に関しては、私はやっぱり、そこそこ適当なところで、逆に終わらせていきたいと思ってます。

Video: 1612.mov

9) The pain involved in dying

死ぬときに痛みを感じること
死ぬときにですね。痛い思いをするのは、5秒か10秒だったらしょうがない。だけど、それが何時間も続く、延々と続く、それだけはもう嫌ですね。もだえ苦しんで死ぬのは嫌。理想は、眠るように。朝起きたら、あ、違う。朝起きてこなかった、あら死んじゃってるわって、そういう死に方が理想です。痛みのだけは、どうしても嫌。うん、痛みはやっぱり怖いです。

数字が大きいのは、痛みに関してもだけだね（笑）

Video: 1613.mov

10) The intellectual degeneration of old age
年老いて知能が落ちていくこと

3

私の両親を見てて、やっぱりこう、だんだん痴呆になっていく。それはもう周りのものとしては辛いし悲しいことだけど、本人、今回は私に関しては、私は知ったこっちゃないよね、きっと（笑）それが感じられるなら痴呆になってないということだから。それはもうそれで。神様からのごほうびだって言う人もありますね。本人には恐怖も痛みもなくなる。感じにくくなっって。だから、私に関しては、ありがとうございますっていうところです。

Video: 1614.mov

11) That your abilities will be limited as you lay dying
死へ向かって横たわるときには、できないことばかりになること

1

自分がいよいよ、そろそろお迎えが来るなってなったとき。早く来てくださいって思うだけですね。いろいろやり残したこととかそういうのは、まったく未練も何もない。ただ、早くお迎え着けてくださいよ。早く連れてってくださいよって思うだけですね。

寝たきり状態になって、生きなければならない、生かされてしまっているというのは私たちにとっては一番辛いことです。身動きができない、しゃべれない、動けない。そういう状態はやっぱり一番怖い。生きてしまう、生きさせるている、それでも生きている状態は、一番怖いっていうか、一番嫌なことです。それだけは勘弁して欲しい。早くお迎えに来てください、そう思う。

Video: 1615.mov

うん、寝たきりになって生きているということに関しては5。

Video: 1616.mov

12) The uncertainty as to how bravely you will face the process of dying
死のプロセスが目前に迫ってきたときにどれだけ勇気を持っているかわからないこと

1

いよいよお迎えが来たぞっていうときに、ああ死ぬんだ、死んでもうんだ、どうしようとは絶対思わない。あ、死ぬんだ、よし行くぞ、まだか（笑）で、一つだけね、心残りとすれば、そういうプロセスをね、こううまく伝えて残してあげたい。今こんなのよ、今こんな状態なのを伝えてあげればおもしろいかない、と思うけど。目の前に来たら、あ、言ったか、そう思うだけだと思う。すっと受け入れられる。

Video: 1617.mov
で、こんなときになって最後に「死にたくない一！」ってわめいたらどうしよう（笑）おもしろいね。笑ってやって。

13) Your lack of control over the process of dying
死のプロセスは自分がコントロールすることができないこと

1
死ぬっていうことは、まぁ体のコントロールがきかなくなる、頭のコントロールも聞かなくななる。そういうことが死ぬことだと思うから。まぁただただ、その時間が長いと困っちゃうなぁ。こうなるべく早く、ずっとこういさせていただけるなら、いかせてください。それは、怖いとかそういういんじゃないね。

Video: 1618.mov

14) The possibility of dying in a hospital away from friends and family
病院で、家族や友人から離れて亡くなる可能性があること

1
最後のときがきて、もし周りが間に合わないと、突然あったとか非常にたった一人。私は、それはしょうがないなって思うし、それのほうがいいのかかもしれないと思う。逆に、死ぬ前に会えなかったって思いは残るかもしれないけど、でもそれは、そうですね。会えないほうがいいこともあるかしれない。最後の場に立ち会ったほうがいいのか、まぁ、そのときそのとき。ほんとそのときにならないとわからないですね。でも自分の身としで、たった一人で死んでいくのね、私寂しいわ、とは思わない。みんな、がんばってね、バイバイっていう感じ。だって、逆に囲いについにいっぱい集まってくれてごめん、私寂しいからならないっていうほうが辛いじゃないですか。だから、もし、一人だったらそれはそれで、私は寂しいと思う。さよなら言うほうが辛いよね。だから、一人ぼっちでも寂しいとは思わない。

＞死ぬのが怖くないとよく言うのはなぜ？
あのね。あ、でもね。今に始まったことじゃないのね。よく考えてみるとね。あの、死ぬということに対して、小さいときは逆にあこがれたりもした。それはでも何もわかってないからそれで。ただその場になったら本当にどうなるかわからない。ただ、今に関しては、死ぬのが怖くないって言うよりもね。死にたい、というのが本音ですね。なぜ、そんなに辛いか死にたいのかや、うん、違うのか。何も別に今は、辛くないのよ。で、あの、不幸か。ぜんぜん不幸じゃない。幸せかって言われたら、幸せなんだと思う。でも、なんだろ。もう、いい。ありがと。お迎えにきてっていうほうが強いから。

毎日が……何が楽しいか。毎日が楽しいかっていっちゃ、まぁ楽しくないわね。楽しいことは、特にない。だけど、楽しくないと早死にたいっていうんじゃないのよね。うーんだろうね。そのときそのとき。例えば孫たちが来てくれる、とっても楽しいよね。一緒に買い物行ったり、とっても楽しいよね。だから、それはそれでとっても楽しい。ありがとうだけどね。うーん、あの。それに、子どもとか孫とかに対しては失礼な話だけ
ど。あのね、悪いけど別ものなの。何か別ものなの。それは、とても大事にしたいし、とても愛してるのよ。けど、これはもっと別もので、やっぱり何だろう。寂しいって言うのは、子どもたちに悪いと思うけど。それとはもっと別のもので、やっぱり何だろう。寂しいって言うの。だから、そっから来てるんだと思う。やっぱりいろんなことがね。

来年で5年。あの、いつまで絶対に、癌されないね。深くなるばかり。だから、それがあるから、なんだろ。それでも。やっぱり、いろんなことをしてきても、させてもらってきな。

知り合ったのが1987年。それから、なんだからで89年にこちらへ来ますね。ということは一番最初に結婚した人よりも、長くなっちゃったの。一番最初の結婚は16年。おじさんとは、だから、87年だから引いてみて。あのね、一緒に暮らしたのっていうかも、一緒にほとんど近くになったのが88年の終わり。だからこちらへ来たのが89年。もうそれからですね。今年は何年？15年？ということは、25年。うーん。

＞おじいちゃんの痴呆を目の当たりにしたことは影響してる？

＞癌だってわかったとき

最初に癌だってわかったとき……あ、来たか。やっちまたかっていう感じだけで。癌になっちゃったっていうショックはなかったですね。なんかずっと入ってきて、あーそっか。やっぱりか、しょうがないっていう感じですね。

＞最初に病院行ったとき

一番最初ね、わかっちゃったらどうしよう。出てきたらどうしようっていうので、やっぱり行くのは怖いっていうより嫌。できることなら知りたくない。できるなら知りたくない、がね。

＞延命治療したのは
本来ね、もう延命治療はしたいたって言ってたけど。今回、えー、エクスキューズなのかもしれないわね。ただやっぱりおじさんが亡くなったあと、がたがたしましよった。「癌ですよ」でしょう。そのまま、コトンといけるんだったらいいけど、そうじゃなかったけど、つまり、ちょっと待ってくださいよっていうのはあった。だから、とあるね。今回、できることは全部やって、それからもう一回仕切り直したらしたかったと思ったから。うーん、そうね。とりあえず、言われたことは、できることは全部やりましょうって思ったのね。

もし、あのまま本当にしなければ、まぁとにかく、一生長生きてしまうことが怖い。まぁ、そうね。あの、衰えていく自分を自分で見るのは嫌。それと、これははっきりひとつ。だんだんはっきりしてきたのはね。やっぱり、やっとこれからちょっととたいまって思ったから。せめて、1年2年、3年。ゆっくりさせて、今回。今は勘弁してよ、と思った。だから、直そうと思った。直そう、うん、直ると思ってないから(笑)うん、とりあえずできるよ。一度すっきりさせましょうと、キーモを受けたことにしました。

Video: 1620.mov

今ね。一番怖いこと嫌なこと。やっぱり、長生きしてしまうことが怖い。まぁ、そうね。あの、衰えていく自分を自分で見るのは嫌。それと、これははっきりひとつ。だんだんはっきりしてきたのはね。だから、直そうと思った。直そう、うん、直ると思ってないから(笑)うん、とりあえずできるよ。一度すっきりさせましょうと、キーモを受けたことにしました。

＞住むところがあって年金が入っても不安？

そう。今の生活だってね。あの、まぁ確かになんていうか、ものすごく始末してないのよ。その自分が馬鹿じゃないって思うわけ。だけど、そんなに雑居もしてないのね。無茶苦茶もしてないわけでも、ただ、始めできるということはいいあるんは思うのね。でも、いるものは正直に MagicMockした。これから残に向けて、ものすごく始めようと思っていた気持ちではなく、いろんなものを整理して、いろんなものを小さなものにできるわけではないと思う。そうなると、今までのようには動けないのって思う。少しは、いろんなことをカットしているのね。努力はしてる。本当に、切り詰めた生活をしようと思ったらまではできない。おじいちゃんやおばあちゃんたちは、大抵の両親のことを見て、あの人たちがどうして生活できたんだろう。どう考えても計算できない。生きていくにはかなり辛い金額しかなかったのに、それでも貯金までしてたって、どうしてたんだろう。そう思うと、思うよ。私は何もしてないっていうか、もう少しできるはずです。じゃあ、もう少しできるのね。それは、もう少しできるのね。 Yorkshireで今年くらいから、そういう方向に今年くらいから、そういう段階に入っています。

やっぱ、そうね。ソリゃ例えば最初の計画のように、言われたように、あるものがあって、何の心配もないはず、また別の生き方もできるかもしれないわ。その、湯水のように使わなくて、こう、ゆっくりと気持的にゆっくり暮らして長生きもできたかもしれない。まぁそれはいいか悪いかはよく分からないけれども。ただ、そうしたかっただということはそう思うわけではない。結局、自分で稼いだお金じゃないじゃない。もう頂けただけだね。それもお金はなかったからと言ってたに、いつまでもね。言ったってしょうがない。ようはタナボタなんだから。あるものでこれだって、ありがたいことなんだから、それをして手にどこまでもつけるかだって。そう思うにちょっとシフトを変わってきてる段階ね。だから、でもそれでも今日明日のことを心配しなくていいわけだからね。何がそんなに心配なのっ
て言われると、それもまた困るんだけれども。まぁ5年はオッケーかもしれないけど10年はオッケーじゃないかもしれないとかね。

そうなのね。いろんなことは結局考えてみる必要があるわね。だから、ま、どっちにしても。これから長生きして……長生きするリスクよりも、適当なところで。おさらばした方が、私自身ハッピーじゃないかと思ってる。それとやっぱり、私がもう一回癌っていうのがくると思う。必ず来ると。でもね私ね、必ず何かなるか、何かあったかと思ったこと、なかったことのよね。ほんとによ。私の予想はすべてはずされるわ。そういう大きな人生の節目においての予想は、これまでもすべて。だから、が、どちらにして。これから先長生きして……長生きするリスクよりも、適当なところ。おさらばした方が、私自身ハッピーじゃないかなと思ってる。それとやっぱり、私もう一回癌っていうのがくるだろう。お金のこともあるけど、やっぱりこう、つれあいが亡くなるっていうのは寂しいよね。一つ、連れ合いがいない。二つ、お金の心配。どこまで。食いつぶしてしまうのが怖い。それが一番大きな要因ですね。

Video: 1621.mov

いやぁほんとにね、お金のことがね、ほんとに心配ならね。例えばインターネット500ギガの契約やめろよと。もっと始めると。そしてこの家も、お家賃で月々やっぱり。4つも部屋いらないしって言うのがね、ほんとには。今更さ、智子が来たときにとか、エックス・ハズバンドさんが来たときにとか、予備の部屋までキープしておく余裕はないだろうとかね。ほんとに、始末しなくてよいんじゃなくては山ほどあって、できる。なのに、しない。うーん、ここが私のねね、私たるゆえんで。意思が強いんだか弱いか。私ね、結局意志が弱いのよ。で、自分でできない分、大きな言い訳として、なるようにしかならないわけて結論に至るわけ。でもなるようにしかならないわけて結論に至るわけ。でもなるようにしかならないわけて結論に至るわけ。でもなるようにしかならないわけて結論に至るわけ。でもなるようにしかならないわけて結論に至るわけ。でもなるようにしかならないわけて結論に至るわけ。でもなるようにしかならないわけて結論に至るわけ。でもなるようにしかならないわけて結論に至るわけ。

いや、でもね、ここしばらく食べなきゃっていうのもあったし。あれだけでもね。こういうものを見てね「あ、今いるか」とか「まだあった」とかね。そういう風に思うようになった。この年にまた。スーパーへ行って、あ、これ今いるじゃないかと思わない？ちょっと。これかわいと思えても、うーん、って思えるようになった（笑）やっと進歩したから。当たり前の Episcopalなけどもね。ただやっぱまだですね。価段見なきゃね。やっぱりね。これはどうしたもんかね。ただ、買うときにこっちっちがあればどっちが安いかっていう時には、安いほうをとるの。でも、いくら安くて、いくらだっただけっていう結論は。どっちが安いかは見てるけど。だからそれがいくらなのかっていうのは見てないという。そこはね、直らないね。しょうがないね。本当にね、お金のことになじってるとか心配なら見よ。考えよと思う。これはもう昔から。きっとね、これは、お父さん。おじいちゃん。大阪のおじいちゃんの血ですね。どんぶり勘定。アパートで。でも、それでも何とかなってきた。だから、いいじゃないかな。きっとこれから先もそうなんだよ。心配してるんだけど、だからって自分で何にもしないため。何もしないじゃないんだよ。結局、できないんだよね。困った。
Appendix 6: Not So Soon final video transcripts and translations for subtitles

Video: 1590.mov
この世にいろんなものを置いていくのはしょうがないよね。棺おけの中に持ってくるわけがないから。[7 sec]
I'll have to leave all I have behind. [30]
It's not like I can take any of it with me. [33]

もう、これはすべてしょうがないね。そのときが来たら、置いていくものは置いていく。[7.5 sec]
It just can’t be helped. [20]
It’ll all be left when the time comes. [31]

Video: 1591.mov
天国とか地獄とかまぁ何かはあると思うけど、[6.5 sec]
I don’t know about Heaven and Hell, [29]
but I do believe there is somewhere, [30]

どこ行かされるかわからないよね。そのときになるまでね。[5.5 sec]
though I won’t know where I’ll go [27]
until the time comes. [18]

だからそれは、怖いっていったってしょうがないよねえ。[4.5 sec]
So there’s no point in being afraid. [30]

だから、それが怖いから死にたくないからとか、[5.5 sec]
There’s no point being afraid [25]
of where I’ll end up [16]

天国行きたいからどうのこうのとかはない。もう、しょうがない。[4.5 sec]
or doing anything special [22]
I hope there’s something I can do, [28]
like look over everyone, but... [25]

I think there’s just no point [24]
in thinking about [15]

それはまったく意味がないと思いますね。[5 sec]
all that I might miss out on once I go. [30]

Video: 1597.mov
別れの日が来たとき。[2 sec]
When the time comes,

やっぱり、行く人はね、もうそれでお終い。まぁ先で何か思ってるのかなんかは分からない。でも残されたものは、

it's the end for the one that's going.

I don't know if or what I'll be feeling.

やっぱり、どんな理由があろうとね。

but it'll be hard for those staying.

やっぱり残されたものは辛いよね。

It'll be hard for those I leave behind.

だから、そういう辛い思いをさせるのは、申し訳ない、と思う。

So I feel bad about the pain I'll cause.

だからそれが怖いか、死ぬことが怖いかっていうことには別ものなのね。

That's what's scary, not dying.

ただ、ごめんねって言うのが、気持ちですね。

I just feel sorry about that.

だから怖いじゃない。

So I'm not scared,

でも、ごめん。

but I'm sorry.
えー。痛みだけは勘弁してください。[3 sec]

Ah, please just spare me the pain. [28]

痛みだけは怖いです。痛みはとってください。[3.5 sec]

I’m only scared of the pain. [23]

Please, no pain. [14]

お願いします。[1.5 sec]

Please. [7]

寝たきり状態になって、生きなければいけない、[4.5 sec]

I would hate to be bedridden [23]

生かされてしまっているというのは私にとっては一番辛いことですね。[7 sec]

or having to live, [15]

being kept alive. [15]

身動きができない。しゃべれない、動けない。[5 sec]

Being immobile.[14]

Not being able to move or speak. [26]

そういう状態はやはり一番怖い。[5.5 sec]

That’s what scares me the most. [26]

理想は、眠るように。朝起きたら、あ、違う。朝起きてもこなかった、[6]

I hope it’ll be like going to sleep, [29]

where I wake up one morning, no, [26]
I don’t wake up one morning.

and I’m like, “ah, I’m dead.”

I just don’t want it to be painful.

I’m scared of the pain.

In terms of life, it’s not that a long one is good.

and a short one isn’t.

It depends on the person.

It’s different for everyone.

And for me,

I’ve had a good run.
And if at the end I start screaming, [29]

“I don’t want to die!” [18]

Just laugh, okay? [15]
Title: Valentine’s Day
February 15, 2016
Theme: Mother–daughter parallel reflections by Yoko

Yesterday was Valentine’s Day.

My husband had made a Valentine’s Day dinner reservation at one of our favorite restaurants so we dropped the kids off at my mum’s and headed out.

Mum lives about 20 minutes away.

I’m grateful she takes the kids anytime we have something on.

But it’s only been in the last few years that she’ll mind the kids so readily.

Even when Mum’s second husband of 25 years was well, I couldn’t leave them with her.

When my twin daughters were born, it was my husband’s parents who, despite getting on in age, came all the way up from Evans Head to stay and help.

My mum did not once come to see me in hospital and it was months before she even came to meet her new grandkids because my stepfather would get jealous.

Even though he’d immigrated here, my stepfather had the finicky traits typical of a Japanese who had lead others for a long time, but he was pretty good towards my siblings and I, his second wife’s family.

We had our differences, but I think we had a fairly good relationship.

I helped out a lot before he died, truly wanting to do all I could for him and I still get all teary when he pops into my mind because of all I am thankful to him for.

Even so, our relationship was, of course, not a real father–daughter relationship. I’m sure we both just put up with a lot for Mum’s sake.

Right about the time my stepfather’s son’s child turned four and was at that really cute stage, he had an unfortunate accident.

He had a brain injury so bad that he was bedridden and unable to even speak.

The accident had nothing to do with my stepfather, but even though years passed, time did nothing to ease the grief he felt.
Whenever my stepfather saw my kids, he’d be overcome with the image of his poor grandson and it was too much.

I remember Mum telling me that she wouldn’t come and see us because even though it was tough having twins, it was a special and joyous tough, and she wanted to consider the feelings of my stepfather who was heartbroken and for whom my babies were a painful reminder.

Mum has always been a bit different to the typical image of a Japanese mother.

My parents also got divorced quite a while ago and I haven’t lived with her since I was a teenager so that’s probably why I just see her as her and me as me.

So when she didn’t come to see me despite being caught up in the raging storm of caring for twins, I didn’t really think much of it.

I was content to just have a bit of a grumble once in a blue moon that she really could have helped out a bit more whenever I thought about it. *laugh*

Still, I think it’s good that Mum always looks after the kids like this for us now and that we have been able to build this kind of relationship.

Thank you, Ma-chan, Mum. Always.

I really treasure the fact Mum enjoys being with the kids and the kids are always saying, “I want to go to Ma-cha’s place!”

Please stick around for a while yet, Mum!

Title: Valentine’s Day
February 15, 2016
Theme: Mother–daughter parallel reflections by Mum

The two of you are going out for Valentine’s dinner on Valentine’s Day.

I’ve taken on the babysitting.

Go and enjoy yourselves.

It’s great you can still go out on dates together even after all these years.

I only hope you continue to get along and are happy for ever and ever.

That’s why I’ll gladly do as much as I can!!

For as long as I can... *giggle*
The other day Mum and I went to Surfers Paradise.

Every year Surfers plays host to the Sand Safari sand festival that is held along its white sandy foreshore.

This year there was also a photography competition as part of the festival and I had two photos entered in the exhibition.

There was a party on that day for the photo exhibition, so I invited Mum to come along since she loves photography.

After the party, the two of us went for an evening stroll along the beach.

Mum was the type of person who never once told me study.

In fact, when I was up late for nights on end studying for my junior high entrance exam, she would actually tell me not to study so much and have more of a break.

I remember, even as a child, being appalled, thinking, “What kind of parent are you?”

When my friend Yuki from next door was studying, her mum would stay up too and make her late-night snacks.

If I was up late studying, Mum would just go off to bed. That’s the kind of mum she was.

But I was also not the type of kid who just did what her parents told her to unquestioningly.

About that time, I was actually right in the middle of a rebellious phase.

Thinking back, there probably weren’t too many kids as difficult as me.

Though I’d always been fiercely independent, I was a rebellious kid that just desperately kept pulling away from my parents. The more they cared, the more I deliberately withdrew from them.

When I think about it now, Mum was probably taking a laissez-faire approach, skillfully putting some distance between us and controlling me from afar.

But I was immature and everything my mum did just provoked me.

I would ignore her and go days without speaking to her.

I laugh when I think back now.

Even when we were out, I would walk as far away from her as possible.
I think I was probably directing all the pent-up emotions of my rebellious period at my mum. Perhaps I was trying to find my place in the world by rejecting her.

I also just couldn’t accept the fact that a mother who had, up until then, been like a goddess to a child growing up, was actually just a normal human being.

This is a terrible time because kids are self-centred and blind to their own faults.

I wanted to be different to my mum when I grew up. I wanted to surpass her and become an even more amazing person. I grew up subconsciously thinking that way.

Telling myself that I was different to my mum was a probably a quick and easy way of recovering from the shock of realising that she was just a living creature, a weak human being.

This went on for several years until one day my parents separated.

I decided to blame my parents’ divorce squarely on my mum.

Her existence became even more unforgivable than anyone else’s.

Then I didn’t really see her again until I was an adult.

That was when I was in my first year of senior high.

A while later Mum moved to Australia and after going to visit her, my feelings towards her gradually started to change.

I’d also grown up. All that time I’d wanted to see her, but hadn’t been able to and when I finally did, I found I was no longer able to deny the love I had for her.

After moving here myself, I was also gradually able to pour out my daughterly grievances to my mum, who had moved out after the divorce.

The strange thing was that the love I had for my mum, who I had thought so unforgivable, quietly diffused each grudge as I vented them to her.

Ultimately, I had wanted Mum to listen to my feelings.

I had wanted to talk more with her.

Maybe that was just what I wanted all along.

Then before I knew it, I had kids of my own.

Now I am painfully aware of how it feels to be a mother.

Lately I increasingly think how much I’m like my mum when I look at my aging self in the mirror.

And now that’s a nice feeling.

For a long time, I was a terrible, unlovable daughter.
I’m sorry, Mum.

I hope that I can be a good daughter and make up for the past for as long as possible.

**Title: A day at Surfers**  
*February 25, 2016*  
**Theme: Mother–daughter parallel reflections by Mum**

The other day my daughter took me to a photography exhibition and party at Surfers Paradise.

Also to the gallery exhibiting the works that she’d entered in the competition, but unfortunately missed out on a prize for.

I was into photography much earlier, but it was her who went on to become a photographer.

Wife, housewife, mother of three, student, photographer, writer...my delicate daughter skillfully able to play any role.

Hats off...

From a young age she hated losing and has always worked hard.

True to her Chinese zodiac, she is a boar through and through...*giggle*

If anything, she is not good at depending on others. She works hard and goes it alone.

I’m sure she could slow down a little, though...

But as her less-than-perfect mum and seeing her constantly doing things, I am reassured, proud and, above all, happy.

Now in my final chapter,

These days I am blessed to have her by my side...

---

**Title: Last chance**  
*March 15, 2016*  
**Theme: Mother–daughter parallel reflections by Yoko**

Now that I have three daughters of my own, I often find myself dreading the day they hit puberty.

One of these days it’ll be my turn to be on the receiving end of all I did to my mum during my rebellious period.
No amount of reflection on my part is going to stop karma.

At least if the girls turn out a bit like their dad...but I don’t hold out much hope of that happening.

My husband is even more strong-willed and obstinate than me so regardless of who our girls take after, they’re already guaranteed to go through difficult rebellious periods.

Triple the girls. Triple the rebellion.

Oh, it’s going to be brutal.

Becoming independent of your parents during puberty has been analysed by Freud, the father of psychoanalysis, through the Oedipus complex and, as has already been discussed in many fields, is a difficult stage most people go through before adulthood.

In early childhood, a child is at one with their mother, learning all about the world through their relationship with her.

They then go through a period called the Oedipal period, where they stop being dependent on their mother, on their parents, via their father who has superior authority and physical abilities as well as social ties.

The process is a bit different for males and females, but for girls the psychological separation from their mother, who is of the same sex, is usually more complex and more difficult than it is for boys.

There are many who are seen and said to have a very close relationship with their mother that go on to become adults without fully differentiating themselves from her and then there are others who display an unusual rebellious spirit towards their mother.

I was definitely the latter.

Oh, I was a terrible daughter...

I’m sure my feelings of remorse are even greater because I’m worried about my now frail mum.

Mum often grumbles, “Cancer is a really terrible disease. Of course, people that suddenly die in an accident one day are also unlucky, but this disease is a death sentence, yet you still have to live the remainder of your life.

But I’m happy I’m able to have this last chance to get my affairs in order and spend time with my children and grandchildren before I die.”

I wonder if people who die without knowing their time is up are fortunate or not?

According to research by academic Feifel (1956), most of the WWI veterans that fought on the threshold of life and death replied that they wanted to die in their sleep, despite not really thinking about death on a daily basis.
They wanted to slip away unknowingly and peacefully in their sleep.

I’m sure there are many people, not just soldiers that have experienced and thought about life and death in extreme situations, who think that way.

There is nothing more bitterly distressing than accepting your own death sentence.

Getting a cancer sentence is cruel. No doubt about it.

But for people diagnosed with cancer, perhaps they have also been given a last chance at life.

How will you live the rest of your life?

How will you spend the last of your time that’s left?

That may be the last chance at life granted only to someone who has had the cruel experience of being confronted with their own death.

I as the daughter have also been given the lucky or unlucky chance to think about Mum’s death and the remaining time I have with her.

Sooner or later everyone dies.

If I’m going to have to accept the fact that my mum will one day die, then, until that time comes, I want to be grateful for being given the chance to spend that time with as few regrets as possible.

I have never really been around, but I am now the ideal daughter, one that is thoughtful, kind and healing just by being present.

I’m not sure myself how much I can do and how long I’ve got to do it.

Mum says she’s not scared of death, just scared of the pain and suffering at the end.

I want to be able to fulfill my mum’s wish to be spared of that, just that, no matter what.

Title: It was a beautiful star-filled night...

March 19, 2016
Theme: Mother–daughter parallel reflections by Mum

It was a beautiful star-filled night...

I was in labour, holding my swollen belly...

Five, six steps, it’s so far...
Rest rest, in the middle of a cold December night, the long walk to the hospital with my dear father carrying me under his arm...

There was nothing he could do to ease my suffering, but support me, yet he remained calm...

While I resented my awfully cold partner...

I glanced up at the sky and it was filled with stars...

I didn’t yet have my own car at the time.

That afternoon I had gone to the hospital when the contractions started.

“The first one always takes time.

Go home and wait for a bit longer”,

they said and sent me home...

I finally made it to the hospital entrance and couldn’t move anymore...

Just then...

A doctor, who had probably been catching up on sleep, carried pregnant me in his arms all the way to the ward!

In all my years, this was the one and only time someone had carried me in their arms, not before and not since...

It’s a shame I was unable to savour it...

I don’t know if it was because I had held on until the last moment or not, but after I entered the delivery room it all went smoothly, and you came out quickly.

Perfectly healthy, thank God...

An angel with jet black hair.

Married at 20, a baby at 21.

Knowing nothing of the world and still a child myself, you made me your mum.

I loved you, oh how I loved you...

I held you and played with you all the while you were awake...

And I watched you all the while you were sleeping...

Then before I knew it, you, my darling, had become a mother of three...

Every year when your birthday draws close, I remember that star-filled sky in the Tama Hills of Kanagawa that December...
Appendix 8: List of Research Outputs/Activities

2014

- Presented the paper “‘For Grief’: Things We Avoid Talking About. Society’s Denial of Death and the Stigmatisation of Funeral Directors” at the 2014 Work in Progress Conference: The Life of Things, University of Queensland, Brisbane, September.

2015

- Presented the paper “For Grief: A Photographic Social Documentary of Funeral Directors and Their Experiences” at the Create World conference at Queensland College of Art (QCA), Griffith University, Brisbane, February.
- *Not So Soon* exhibition at the Create World conference at QCA, Griffith University, February.

- “For Grief: A Photographic Social Documentary of Funeral Directors and Their Experiences” is published in the Create World 2015 Conference proceedings.

- Presented the paper “Not So Soon: Dying with Denial, Fear and Acceptance” at the Death, Dying and the Undead: Contemporary Approaches and Practices conference by Australian Death Studies Network, Central Queensland University, Sunshine Coast, October.

- Two photographs were selected for the Sand Safari Festival photography exhibition at Surfers Paradise, February.

2016

- Held a solo exhibition at Depot II Gallery as an associate exhibitor of HeadOn Photography Festival, Sydney, May.
- Participated in Live Book Making Project at HeadOn Photography Festival and created a photo book with a professional book designer who is a member of Australian Book Designers Association, provided by the project, Sydney, May.
- Presented the paper “Not So Soon: A Case Study of a Mother–Daughter Relationship amid the Fear of the Mother’s Impending Death” at the Australian Women’s and Gender Studies conference at QUT, Brisbane, June.

2017

- Participated in the group exhibition *Erehwon* at POP Gallery, Brisbane, January
133

- Exhibition catalogue *Erewhon: from nowhere to now here* (ISBN: 978-1-925455-403) was published, Brisbane, January.

Online exhibition catalogue: [https://issuu.com/yokolance/docs/erehwon](https://issuu.com/yokolance/docs/erehwon)

2018

- Participating BrisAsia 2018 Symposium at Queensland Performing Centre in Brisbane as a panellist, Brisbane, February.

- The book *Not So Soon* will be published, Gold Coast, May.
Solo exhibition at the Webb Gallery will be held, QCA, Brisbane, May.
Reference List


Lance, Yoko. 2013b. "For Grief." Bachelor of Digital Media with Honours Exegesis, Queensland College of Arts, Griffith University.


Saiyogo. 1187. [Ancient Poem].


Zheng, Wei. 636. *Book of Sui Vol. 81 Liezhuan (Biographies ) 46, the Dongyi*. Don, China.
Reference List of images


http://mrtoledano.com/photo/days-with-my-father/item/5/.

Acknowledgements
Bruce, Susan. 2007. "Sympathy For the Dead: (G)hosts, Hostilities and Mediums in Alejandro Amenábar’s The Others and Postmortem Photography." Discourse 27 (2) : 21-40.


Gilltrap, Helen. 2012. On the suitability of the Southport General Cemetery being placed on the Gold Coast local heritage register according to the principles of the Australia ICOMOS Charter for places of cultural significance 1999, known as the Burra Charter. Gold Coast.


Monk, Katherine. 2009. Preparation for the Final Voyage; Departures Teaches Us There is Nothing to Fear about Death. Vancouver, B.C: Infomart, a division of Postmedia Network Inc.


