Re-imagining patient narrative: exploring patient experience of genetic medicine through art practice

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Re-imagining Patient Narrative:
Exploring patient experience of genetic medicine through art practice

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A thesis submitted in partial fulfilment of the requirement of Sheffield Hallam
University for the degree of Doctor of Philosophy

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Declaration

I, Emma Frances O'Connor, declare that the enclosed submission for the degree of Doctor of Philosophy, and consisting of a written thesis and an accompanying body of art work entitled *Pé de Grue,* meets the regulations stated in the handbook for the mode of submission selected and approved by the Research Degrees Sub-Committee of Sheffield Hallam University.

I declare that this submission is my own work, and has not been submitted for any other academic award. The use of all materials from sources other than my own work has been properly and fully acknowledged.

Abstract

Re-imagining Patient Narrative:
Exploring patient experience of genetic medicine through art practice

I contend that art practice can critique and have an impact on the expectation and form of the patient narrative of genetic medicine, as promoted and experienced in medical contexts, and this is proposed as a contribution to knowledge. My second – methodological – contribution lies in the expansion of autoethnography to include autobiographical art practice to amplify possibilities for insight and new understanding.

I construct and reflect upon my patient narrative as an artist and carrier of the CDH1 genetic mutation, associated primarily with Hereditary Diffuse Gastric Cancer. Art practice is proposed as a means of documenting, articulating, and analysing patient experience of genetic diagnosis and preventative surgery. Art works are employed to examine the relation between genetic diagnosis and patient narrative, with attention to the CDH1 genetic mutation. The discourse and structure of patient narrative are considered, questioning if current definitions accommodate the complex relation between genetic diagnosis and patient narrative.

I trace the historical emergence of patient narrative (the means by which a self-identifying patient or family member articulates personal experience of illness), examining dominant ideas in the field of patient narrative: biographical disruption, narrative reconstruction, and the sociologist Arthur Frank's typologies of illness narrative. I explore Frank's ideal illness narrative – the quest narrative – in my own quest, led by art practice, to locate my stomach. Contextualising my work in this field, I construct new ways to explore my patient experience through art practice, challenging existing models that fail to reveal what it means to be a patient of genetic medicine.

Autoethnography is both a research methodology and outcome, informed by my experience. The work of others enhances my understanding of different approaches to narrative, providing models for addressing patient narrative in a meaningful way. Readings of two films by Jean-Luc Godard, *Passion* (1982) and *Scénario du film 'Passion'* (1982), and Dora García's film *The Joycean Society* (2013) provide a framework for my practical experimentation as I discover narrative elements to explore through production. Recognising the experimental potential of narrative formation, I work with movement, rhythm, reflection, opacity, focus, emplotment, sequence, editing, fragment, sound, staging, framing, light, and documentation, investigating narrative forms – sonic, haptic, performed, embodied, book, digital – and singular, dialogic, and multiple narratives.

Time thickens, takes on flesh, becomes artistically visible; likewise, space becomes charged and responsive to the movement of time, plot and history.

— Mikhail M. Bakhtin

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Emma O'Connor

Sheffield, July 2017

Records Scanned

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Ref: HSU/PJN/N648714
Date: 26/07/06

DISCHARGE SUMMARY

CONSULTANT: MR HENRY SUE-LING

Dear Dr Jones

RE: Emma O'CONNOR (19.03.80) Croft Cottage, 24 Longcroft Park, BEVERLEY HU17 7DY

Date of operation:	03.07.06
Date of discharge:	14.07.06
Diagnosis:	Strong family history of Gastric Cancer: e-cadherin positive
Operation:	Prophylactic gastrectomy
Surgeon:	Mr H M Sue-Ling Mr S Fenwick

History:

This is just to let you know that this patient of yours underwent the above procedure and was discharged home well 11 days later. A simple prophylactic total gastrectomy was performed and a feeding jejunostomy was inserted at the same time to provide nutritional support for Emma in the first 6 months after her surgery. Emma has been taught how to use the feeding jejunostomy and is going to manage this at home. She will also require B12 injections every 3-6 months and supplements from time to time.

The final histology was reviewed at our Upper GI MDT Meeting. There was no apparent tumour found in the specimen, though further blocks were going to be taken and sent to Portugal for further analysis. Interestingly her father who also had a prophylactic gastrectomy by myself a few years ago was found to have a small foci intramucosal carcinoma. With your permission I have arranged to review Emma in 6 weeks time to see how she is getting on.

With kind regards,

Yours sincerely,

MR HENRY M. SUE-LING MD FRCS
Consultant Surgeon

cc. Dr Carol Chu
Consultant in Clinical Genetics

Introduction

Patient Narrative and the CDH1 Genetic Mutation —
My Early Genetic Experience — Illness, Suffering, and Art — Rationale —
Research Aims — Thesis Structure

Patient Narrative and the CDH1 Genetic Mutation

Current uses of the term *patient narrative* extend to include: narratives told by medical practitioners to communicate clinical knowledge; narrative as a clinical interview tool;[1] patients' narratives on entrepreneurial patient advocacy websites; and the use of narrative by patients and their relatives and carers to articulate the effect of illness and suffering in their own lives. This research pertains to the latter – patient narratives are understood as the means by which a self-identifying patient or family member records and articulates personal experience of genetic conditions.

This work is informed by my experience as a carrier of the CDH1 genetic mutation for Hereditary Diffuse Gastric Cancer (HDGC), a rare genetic condition, and as a patient who has undergone a prophylactic total gastrectomy.[2] While my experience informs the work as the focus for investigations into genetic patient narratives, the research extends to broader stories about genetics and preventative surgery. Gastric cancer is currently the second most common cause of cancer mortality, accounting for around 9.7 percent of cancer deaths worldwide.[3] Of these gastric cancers, 1 to

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[1] Lars-Christer Hyden, 'Medicine and Narrative', in *Routledge Encyclopaedia of Narrative Theory,* edited by David Herman, Manfred Jahn, and Marie-Laure Ryan, Abingdon: Routledge, 2005, p. 408.

[2] A prophylactic total gastrectomy is the removal of the entire stomach as a preventative measure.

[3] Jacques Ferlay, et al., 'Estimates of Worldwide Burden of Cancer in 2008: GLOBOCAN 2008', *International Journal of Cancer*, 127, 2010, 2893–2917 <http://dx.doi.org/10.1002/ijc.25516>. Cited in Xinxue Liu, Susan Richardson, Richard H. Hardwick, Sarah Dwerryhouse, Carlos Caldas, Rebecca C. Fitzgerald, Elizabeth Worster, 'The Impact of Prophylactic Total Gastrectomy on Health Related Quality of Life: A Prospective Cohort Study', *Annals of Surgery,* 260, 1, 2014, 87–93, p. 87.

3 percent arise from a hereditary predisposition syndrome, of which HDGC is an example.[4]

My Early Genetic Experience

When I first became aware of HDGC in my family, my understanding of the condition was limited. I knew that my father carried the mutation associated with HDGC and that therefore my sister and I both had a fifty percent chance of carrying it. I knew that if either my sister or I had the mutation, we would have an eighty-five percent chance of HDGC; that once detected there was no chance of recovery; that my father's mother, Maisie, had died of stomach cancer before I was born; that half of my father's fifty-odd first cousins had passed away, with his cousin Lorraine dying from HDGC at twenty-seven years old.

From a clinical perspective, this meant that I qualified for diagnostic testing. I thought long about what to do and was required to speak with a genetics counsellor. I searched for information, making countless phone calls to try to decipher how other gastrectomy patients had fared. I was anxious to know whether these patients had maintained a stable weight post-operatively. Would my life continue as it had without a stomach? Would I be able to have children? Had anyone died in surgery? What were the options regarding screening? Would regular endoscopies detect HDGC early enough? I faced a lacuna in existing knowledge, making decision-making difficult.

My role as detective proved largely fruitless; the CDH1 mutation was a relatively new discovery and a rare genetic condition. I underwent a genetic test in 2005, and although I have little recollection of having my blood taken, memories of my

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[4] Jenny M. Varley, et al., 'An Extended Li-Fraumeni Kindred with Gastric Carcinoma and a Codon 175 Mutation in TP53', *Journal of Medical Genetics*, 32, 1995, 942–45, and C La Vecchia and others, 'Family History and the Risk of Stomach and Colorectal Cancer', *Cancer,* 70, 1992, 50–55. & H. F. Vasen, et al., 'Cancer Risk in Families with Hereditary Nonpolyposis Colorectal Cancer Diagnosed by Mutation Analysis', *Gastroenterology,* 110, 1996, 1020–27. Cited in, Xinxue Liu, Susan Richardson, Richard H. Hardwick *et al.*, 'The Impact of Prophylactic Total Gastrectomy on Health Related Quality of Life: A Prospective Cohort Study', *Annals of Surgery,* 260, 1, 2014, 87–93, p. 87.

diagnosis are clear. Everything was perfectly staged and my family and I were all given our ‘scripts’. Although my sister and I would receive our results on the same day, our geneticist advised that it would be unwise to receive our results together; my mother and sister went to the hospital in the morning and my father and I in the afternoon. Only later would we meet at home and share our diagnoses. We were prepared for exactly what would happen in the geneticist’s room: where we would all be sitting, exactly what the geneticist would say. We were told that on the table would be a brown envelope containing our diagnosis, that the envelope would not have been opened, that the geneticist would not know our diagnosis. We were not to read anything into any non-verbal language she communicated.[5]

A few months after receiving my diagnosis I had a preventative gastrectomy. Convinced I was going to die, I had a wake the weekend before, inviting my friends for a party. I took my camera into hospital but was not well enough to photograph.

Previous attempts to reveal my own patient experience resulted in a partial retelling. Some elements resisted telling, while others were dominant, excluding strands less easily articulated or needing time to be understood more completely. Complexity was sacrificed in the making of a coherent and ordered story; some parts were lost entirely. I explore ways of communicating my private experiences of this time, including bodily experiences such as pain as well as experiences concerning the fragility of life and the possibility of ultimate aloneness through art practice.

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[5] I have no idea why I agreed to this staged, scripted situation, though it continues to be a generative space for production, resulting in a video and text work, exhibited for my M.A. Fine Art at Sheffield Hallam University, June 2013.

Illness, Suffering, and Art

English, which can express the thoughts of Hamlet and the tragedy of Lear, has no words for the shiver and the headache.[6]

In 'On Being Ill' Virginia Woolf addresses the inability of language to communicate personal, embodied experiences. The person experiencing pain has no recourse other than to draw on the sounds in her/his repertoire to communicate her/his experience, and 'coin the words [her-] himself'.[7] Elaine Scarry, regarding the ineffability of pain, echoes that the realities of such feelings are outside the possibilities of language and representation.[8]

Despite the prevalence of this position in literature on pain – that the reality of feelings such as pain are outside the possibilities of language and representation – historian Joanna Bourke in *The Story of Pain: From Prayer to Painkillers*, writes that writers, having acknowledged the difficulties in communicating their pain, nonetheless proceed to elegantly communicate their experience.[9]

This work is informed by an already established body of textual and visual practice which addresses the experience of illness and suffering. A discussion of some of these precursors to this work ensues, demonstrating how art might be used to critique and have an impact on the expectation and form of patient narrative. These works, along with a corresponding body of academic literature, establish the landscape from where this research extends.

Alphonse Daudet's short novel *In the Land of Pain* provides an eloquent example of a textual articulation of illness and suffering. *In the Land of Pain* chronicles Daudet's

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6 Virginia Woolf, *On Being Ill*, Ashfield, MA: Paris Press, 2002, p. 6 [London: The Hogarth Press, 1930].

7 Woolf, *On Being Ill*, p. 7.

8 Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World*, Oxford: Oxford University Press, 1985.

9 Joanna Bourke, *The Story of Pain: From Prayer to Painkillers*, Oxford: Oxford University Press, 2014.

experience of the then incurable disease, syphilis. Throughout his illness, Daudet recorded his experience of syphilis in a fragmented note-form – notes first published posthumously by his wife as *La Doulou*. Daudet writes intricately about pain, his symptoms and their various treatments, his feelings towards his illness and its effects on people around him, as well as the suffering of others who share his diagnosis. Despite its treatment of a distressing subject, the tone of Daudet's writing is stoic and often humorous. While the fragment – and to a lesser extent humour – is key to many of my works, unlike *In the Land of Pain,* my experience of genetic medicine (and narratives thereof), does not concern symptoms or treatments, and only rarely pain. More recent examples of literary works that address experience of illness, informing this work, include Joan Didion's *A Year of Magical Thinking*, Lauren Slater's *Lying*, Tom Watts' *Patient*, Marion Coutts' *The Iceberg*, and Tom Lubbock's *Until Further Notice, I Am Alive*.

Jo Spence is a much written about artist whose autoethnographic methodologies chart her life, in particular her struggle with breast cancer. Spence worked as a professional photographer as well as in community arts and teaching; she was also a member of the photography collective, *the Hackney Flashers* (1974–1980), working experimentally to address social and economic issues, deconstructing myths and stereotypes related to the role of women in their society. Spence's *Cancer Shock* (1982) is a photo novel addressing her experience of breast cancer through a montage of photographs, documentation, first person writing, newspaper clippings, lists, and quotations. Spence and Terry Dennett's *The Picture of Health?* (1982–6) is a photographic series documenting Spence's experience of cancer treatment in the NHS, her lumpectomy, and use of alternative health therapies. *Photo-therapy,* a collaboration between Spence and photographer Rosy Martin, employs techniques from co-counselling and psychodrama to represent the potentiality (not fixity) of character in portraiture, producing photographic works which allow for the representation of multiple, fragmented selves.[10] *Photo-therapy* inverts the power relationship between photographer and subject, who

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[10] Rosy Martin and Jo Spence, *Jo Spence, Work Index* <http://www.jospence.org/work_index.html> [accessed 28 June 2017].

maintains control over the image produced while using the photography session to work through personal histories and traumatic experiences.[11] In this way, the agentic subject of the photograph re-writes and acts out personal narratives.[12] Spence's *Narratives of Disease* explores the expression of living with cancer through medical and non-medical language.[13] *Final Project* is Spence's last project before dying of leukaemia in 1992. Iconography of death saturates the work, which is a photographic response to her illness and exploration of the potentiality of photography to represent the 'unrepresentable'.[14]

During a recent breast cancer scare following a routine hospital appointment, I could not get the words *Cancer Shock* out of my mind, where a slide show of images from *Cancer Shock* and *The Picture of Health?* played on repeat. I revisited Spence's work, reflecting on its relation to my work. Central to Spence's approach is putting what is seldom seen – images of the body with illness, for example – into the public, where their very existence opens up medical discourse and the patient experience, questioning the power of the medical profession, and giving voice to those voices that were hitherto silenced. I make work about my, often private, experience of genetic medicine, placing it in the world. Yet, works dealing with illness are now commonplace, with the patient voice established in medical discourse.

The work of filmmakers who address experience of illness further informs the context of this research. Derek Jarman's film *Blue* is structured as an experiential account of his illness with AIDS. We see an 'empty' monochrome blue screen while a soundtrack is heard, collaging diary entries, poems, fragments, and conversations. Jarman's painterly, layered autobiographical approach suggests plurality rather than a fixing of identity and while Jarman is very present in the work, unlike in Spence's work, there are no images

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[11] *Jo Spence: Work (Part I & II),* Exhibition Guide, Edited by Terry Dennett, Paul Pieroni, Joe Scotland, Louise Shelley and George Vasey, Jo Spence Memorial Archive, London: SPACE and Studio Voltaire, 2012 <http://www.studiovoltaire.org/wp-content/uploads/2015/11/Jo-Spence-Exhibition-Guide-web.pdf> [accessed 28 June 2017].

[12] George Vasey, *Jo Spence, Biography* <http://www.jospence.org/biography.html> [accessed 28 June 2017].

[13] Rosy Martin and Jo Spence, *Jo Spence, Work Index* <http://www.jospence.org/work_index.html> [accessed 28 June 2017].

[14] George Vasey, *Jo Spence, Biography* <http://www.jospence.org/biography.html> [accessed 28 June 2017].

of him. In *Blue,* the absence of sequences of images, the language of cinema, affects how the viewer, who has no visual points of narrative reference, perceives time.

Stephen Dwoskin's *Trying to Kiss the Moon* (1994) is a feature length (96 minute) colour video with sound. An autobiographical film spanning 50 years, *Trying to Kiss the Moon* is archival, material, and investigative.[15] Dwoskin uses multiple media formats – fragments of black and white home movies, his professional work, as well as film in multiple formats, and video – to document and examine a life. *Trying to Kiss the Moon* is reflective, as one media looks at another media. Dwoskin discusses images with others – a family photo album with his mother, for example – which adds a layer of reflectivity to the work. Dwoskin's use of the handheld camera brings a particular painterly movement to the work – one that is at times full of the energy of discovery and at others, a softer, gentler looking.[16] The movement of body and gesture figures in the work and bodies repeatedly fall down. Other people in the work include Dwoskin's family and a multitude of naked female bodies. Fragments of images and sequences are edited and assembled in an order that despite feeling organic (based on colours, textures, rhythms and the feel of the work) appears relatively chronological.

Viewing *Trying to Kiss the Moon* I am struck by a division – Dwoskin before Polio and Dwoskin after and fragmented transition between the two. In the literature on patient narrative (see pages 22–24) the traumatic onset of his illness might be termed biographical disruption; in this regard, *Trying to Kiss the Moon* exemplifies a biographical illness narrative.

Dwoskin's *Intoxicated by my Illness* (2001) is a film made with layers of superimposed images with a filmic and orchestral soundtrack. The images are of hospital scenes, of Dwoskin in hospital, and of nurses, and other women's' bodies engaged in bondage.

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15 Laura Mulvey talks about Dwoskin's approach as a detached investigation rather than a record, in Essay Film Festival Prelude 1: The Cinema of Stephen Dwoskin and Trying to Kiss the Moon, February 2018, at Birkbeck Institute for the Moving Image, in collaboration with Reading School of Art.

16 Rachel Garfield talks about Dwoskin's choice of film stock and use of soft shadow as painterly in Essay Film Festival Prelude 1: The Cinema of Stephen Dwoskin and Trying to Kiss the Moon, February 2018, at Birkbeck Institute for the Moving Image, in collaboration with Reading School of Art.

There is whipping, open mouths, masked and unmasked faces, and Dwoskin in a hospital bed with a lot of tubes in his body. Although I find the film troubling, it stimulates reflection on cultural representations bodily illness and sexuality, prompting questions about what it is to be ill, opening up medical discourse and the patient experience. It reminds me of a philosophy lecturer at St Andrews University requesting that when writing our phenomenology essays, we should use examples of pain because she did not want us to write about the pleasure of orgasms. Although I recall this with humour, as I view *Intoxicated by my Illness* I think about the possible interchangability of the subjective experiences of pleasure of pain – both philosophically and in my own experience. In *Part 2* of the film, the footage is overexposed and appears surreal. Music is accompanied by the sounds of hospital. We see a submissive, passive body with so many tubes and drips. Dwoskin's approach seems to concern eroticism as much as his illness, his dying.

Lynn Hershman-Leeson takes a different approach in her four-part video work *The Electronic Diaries* (1985–1990). In the first part, *Confessions of a Chameleon,* she talks to the camera, speaking about the illness she suffered when she was pregnant, different characters, and the difficulties in believing what is real. In the second part, *Binge,* she speaks about her relationship with food, her self-abuse, and quest for hunger and fulfilment. It is a diaristic, confessional, and self-reflexive work, as she speaks of life as the ultimate editing process. It is also essayistic, as Hershman-Leeson imparts a wealth of knowledge that connects her own experience with wider society and culture – the word 'calorie', she says, was invented in 1890, and in 1930 the idea of calorie counting came into use. In part 3, *First Person Plural*, Hershman-Leeson includes film footage of Dracula, introducing the idea that we see each other as heroes or anti-heroes. She says it helps her to talk, acknowledging the pain involved in listening. I find it a very affecting work. She talks about violence and not having talked previously. In part 4, *Shadows Song,* a second person is introduced and the work cuts between Henry Wilhite and Hershman-Leeson telling their stories. Hospital letters are superimposed over the footage of Hershman-Leeson speaking. She seeks alternative therapy and her illness disappears, he is not so lucky and dies. It is a very sad ending for me. Some of my textual work deals explicitly with my thinking through dying and as I watch

Shadows Song I relate to the questions Hershman-Leeson raises about dying and control. They are very direct yet tender stories.

Daria Martin works across and between disciplines in different media. Her work attends to themes that include empathy (between self and other, viewer and art, internal and external space), visualisation, the experience of film, ways of looking, and the sensory continuum.[17] Martin's research-based trilogy of 16mm films – *Sensorium Tests* (2012), *At The Threshold* (2014–2015), and *Theatre of the Tender* (2016) – explores the neurological condition mirror-touch synesthesia.[18] Not only does Martin's work open up the medical discourse and patient experience of mirror touch synesthesia but in its examination of how touch might collapse spaces between self and other, viewer and art, internal and external space;[19] Martin's work raises social, cultural, and political questions about empathy – its potential uses and effects.[20]

Martin's *One of the things that makes me doubt* (2010–2011) layers her grandmother's dream paintings and diary entries (read by actors) with outtakes from Martin's earlier films, creating a narrative between generations. In troubling the expectation of a confessional video style,[21] *One of the things that makes me doubt* is open to new meanings.[22]

Andrew Kötting's film *Gallivant* documents a journey made by Kötting, his daughter Eden, and his grandmother Gladys, around Britain's coastline. Eden was born with a

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[17] My Ma (Hons) Philosophy at St Andrews University final dissertation explored the individuation of the senses, troubling their differentiation and arguing for their understanding as existing on a continuum.

[18] Lucy Reynolds, Double Take—Daria Martin's "At The Threshold"', Art Agenda, New York, 10 March 2016, <http://www.art-agenda.com/reviews/double-take%E2%80%94daria-martins-%E2%80%9Cat-the-threshold%E2%80%9D/> [accessed 26 March 2018].

[19] Daria Martin 'Feeling In', Mirror-touch: Synaesthesia and the social, video recordings, The Tate, 7 February 2014, <http://www.tate.org.uk/context-comment/video/mirror-touch-synaesthesia-social-video-recording> [accessed 26 March 2018].

[20] Morgan Quaintance, 'Daria Martin's "At The Threshold"', Art Agenda, New York, 10 March 2016, <http://www.art-agenda.com/reviews/double-take%E2%80%94daria-martins-%E2%80%9Cat-the-threshold%E2%80%9D/> [accessed 26 March 2018].

[21] California College of the Arts, CCA Wattis Institute for Contemporary Arts, Kent and Vicki Logan Galleries <http://archive.wattis.org/calendar/one-things-makes-me-doubt>[accessed 26 March 2018].

[22] 'A Practice for Everyday Life', http://apracticeforeverydaylife.com/projects/daria-martin-one-of-the-things-that-makes-me-doubt [accessed 26 March 2018].

rare genetic disorder – Joubert Syndrome – and *Gallivant* depicts Eden's way of relating to the world as well as the director–daughter–grandmother relationships. *The Pits* (2000) by David Critchley articulates experiences of clinical depression *via* a patient-doctor discussion. *It's Inside: The story of a cancer* (2005) by Katherine Meynell and Alistair Skinner addresses the representation and experience of disease. *A Prayer Before Birth* (1991) directed by Jacqui Duckworth explores Duckworth's experience of multiple sclerosis, and Cherry Smyth's poems and short stories, written for Duckworth.

Noski Deville's *Loss of Heat* (1994) explores coping, accepting, and care in a relationship where one partner has epilepsy. Extreme close-ups of the eyes and face are accompanied by female voices retelling stories from childhood. Conversations in the home between the couple hint at having been told before and I wonder whether there is a disturbance in memory for someone with epilepsy. It is dreamlike and at times nightmarish; the words allude to a muddying between what is real and fictional. Much of the footage is inside what appears to be a home, and this is interspersed with exterior scenes of footage of fields of sunflowers. Colour is significant in the film and it seems that epilepsy is experienced in this way. The two women in the film recite love poetry. Their dialogue feels staged, making me question the place of authenticity in the work.

A discussion of artists' works and processes that capture experience of illness – without necessarily considering how they practically interface with or influence the medical community – suggests the potentiality of methods drawn from art practice to narrate patient experience of genetic medicine. However, while the import of the artists' unique works and processes cited in this section for this study cannot be overstated, none relate to experience of genetics.

Hershman-Leeson in *The Electronic Diaries*, for example, speaks about the growth inside her, whereas I have not been ill. Dwoskin's *Trying to Kiss the Moon* and *Intoxicated by my Illness* explore his experiences of Polio, a wildly different illness to my experience of genetic medicine. These differences stem from – and indeed draw out – the specificity of genetic medicine, as I experience it. Spence was diagnosed with breast cancer, Jarman with AIDS, Hershman-Leeson with a tumour, and Dowkin with Polio. Unlike the artists considered, I have not been diagnosed with an illness. Rather, I received a genetic diagnosis for the risk of an illness, not its event. Unlike Daudet, I have no symptoms and there is no bodily manifestation of my diagnosis. Breast cancer differs from Hereditary Diffuse Gastric Cancer, which is diffuse – its presence and location continue to be the object of ever increasingly sophisticated ways of looking and screening. My experience of genetic medicine does not manifest in a visible, bodily location. The word *diffuse* is significant in terms of my narratives.

Reflection on how these artists approach illness in their practice and consideration of how their works and processes open up medical discourse and the patient experience, strengthens the rationale for using art practice to explore the narration of experiences of genetic medicine. However, reflection on the precursors to this work draws out how a genetic illness is experienced differently.

In the following chapter, I write in detail about how genetic illness poses particular challenges to the narration of patient experience, which coalesce around patient identity, time, plot, closure, risk, and indeterminacy. A growing body of literature in the medical humanities points to the potentiality of methods drawn from art practice to narrate patient experience of genetics.[23] This presents an avenue for experimentation as I construct new ways to explore my patient experience through a responsive and fluid art practice, expanding the array of narrative resources available to articulate my patient experiences.

My work does not begin from the acceptance of Scarry's claim regarding the ineffability of experiences such as pain; rather, I take this as a line of enquiry. The complex and multifaceted nature of my genetic patient experience suggests a compelling subject for investigation through visual and textual strategies. In the context of genetic diagnosis and preventative surgery, my research explores the

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[23] Please see, for example: Ann Jurecic, *Illness as Narrative,* Pittsburgh, PA: University of Pittsburgh Press, 2012, p. 29–38; Priscilla Wald and Clayton, Jay, 'Editors' preface: Genomics in Literature, Visual Arts, and Culture', *Literature and Medicine,* 26, 1, 2007, p. vi–xvi.

potentiality of art practice to examine patient narrative, producing a body of work that is intended to inhabit the clinical field, to open up medical discourse and the patient experience.

Rationale

As awareness of hereditary conditions increases, so does interest in the role played by genetics from determining health to posing challenging ethical issues. The experiences of patients who have undergone genetic testing and prophylactic surgery elicit medical attention, suggesting that patient experiences are not wholly captured by the diagnostic data. Patient experiences of genetic diagnosis and elective surgery are of interest to the medical community, to further medics' understanding of how genetic conditions are experienced and as a source of information for patients and their families to enable informed decision-making. In *Genetics and Society* sociologist Anne Kerr writes that most research into patients' experiences of genetic conditions focuses on their making choices about genetic tests.[24] Post-gastrectomy, I have been asked on several occasions by the research nurses involved in the familial gastric cancer study at Cambridge University Hospitals – which 'aims to identify new gastric cancer predisposing genes and to improve the treatment and management of individuals with an inherited predisposition to cancer' – to share my experiences with other patients. Each time I register with a new GP practice, I find that the CDH1 mutation for HDGC is unknown and I have to inform the GP about my condition, advising on what medication I think I ought to be taking and what further screening I need. Through maintaining contact with medical researchers and doctors in genetics, I hope that this work, through its articulation of my experience of genetic testing and preventative surgery, builds on knowledge of how genetic medicine is experienced.

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24 Anne Kerr, *Genetics and Society: A Sociology of Disease*, London: Routledge, 2004, p. 6.

Research Aims

My aim in this research is to use art practice to examine and communicate my experience of genetic medicine. I construct and reflect on my patient narrative as an artist and carrier of the CDH1 genetic mutation, associated primarily with Hereditary Diffuse Gastric Cancer. I examine the relation between genetic diagnosis and patient narrative. The discourse and structure of patient narrative are considered, questioning whether current definitions accommodate the complex relation between genetic diagnosis and patient narrative. I invite interdisciplinary dialogue on the potential application of patient narrative, as informed by and told through art practice.

Thesis Outline

This thesis is comprised of four chapters. Set at the interstices between the four chapters, is a pedigree diagram – *Pé de Grue* – orientating the reader to my works and their relation to the proceeding chapter. The *Pé de Grue* echoes the use of the pedigree in genetics – at the time of my genetic testing, geneticists drew my family history with a pedigree diagram. Exposure to new ideas and narrative techniques changes my relation to individual works: I return to works made previously with new relations to the works. This temporal dimension – the temporal dimension of narrative – is reflected in the occurrence and reoccurrence of works in the *Pé de Grue* diagrams, as I direct my reader through what may at times seem a repetition, but is a working through. Documentation of my art practice, which constitutes the practical component of this Ph.D. submission, is found in the accompanying volume entitled *Pé de Grue,* which uses the pedigree diagram for orientation, navigating the reader around the works. This accompanying volume – *Pé de Grue* – also contains a duplication of the description of works found after the *Pé de Grue* at the interstice between the thesis chapters, further guiding the reader to the work. All the video works, which are on DVDs in the accompanying *Pé de Grue* volume are duplicated on a memory stick, for ease of reading. Illustrations of the work are not included in the thesis, rather this can be found in the accompanying *Pé de Grue* volume.

Two appendectomies – *ANAMNESIS I* and *ANAMNESIS II* – are bound separately and placed together with the thesis.

Patient Narrative Parts I, II, & III

My opening chapter is a historical contextualising of patient narrative and a discussion and critique of the current field. I examine examples of patient narratives and consider prominent theoretical ideas in the field: biographical disruption, narrative reconstruction, and the sociologist Arthur Frank's typologies of illness narrative. Patient narratives are positioned as a search for meaning and I situate my work as a challenge, not directed towards modern medicine *per se*, but the current pervasive use of restrictive narrative structures to articulate patient experience. I move towards a focus on the specific challenges to patient narrative that genetic conditions pose.

Linhas de Vapor

My second chapter is dedicated to methodology and method. I critically examine methods of looking, watching, and analysing as ways of elucidating narrative strategies, exploring how these methods might facilitate my own work. I write about my practice as method, as a mode of experimenting and finding out. Ethical considerations, fundamental to this enquiry, are considered with particular relation to autoethnographic practices, which require an ethics of self-care. Autoethnography is considered as a process and product. I expand common conceptions of autoethnography to include autobiographical art practices, making a methodological insight, which proposes art practice in autoethnography.

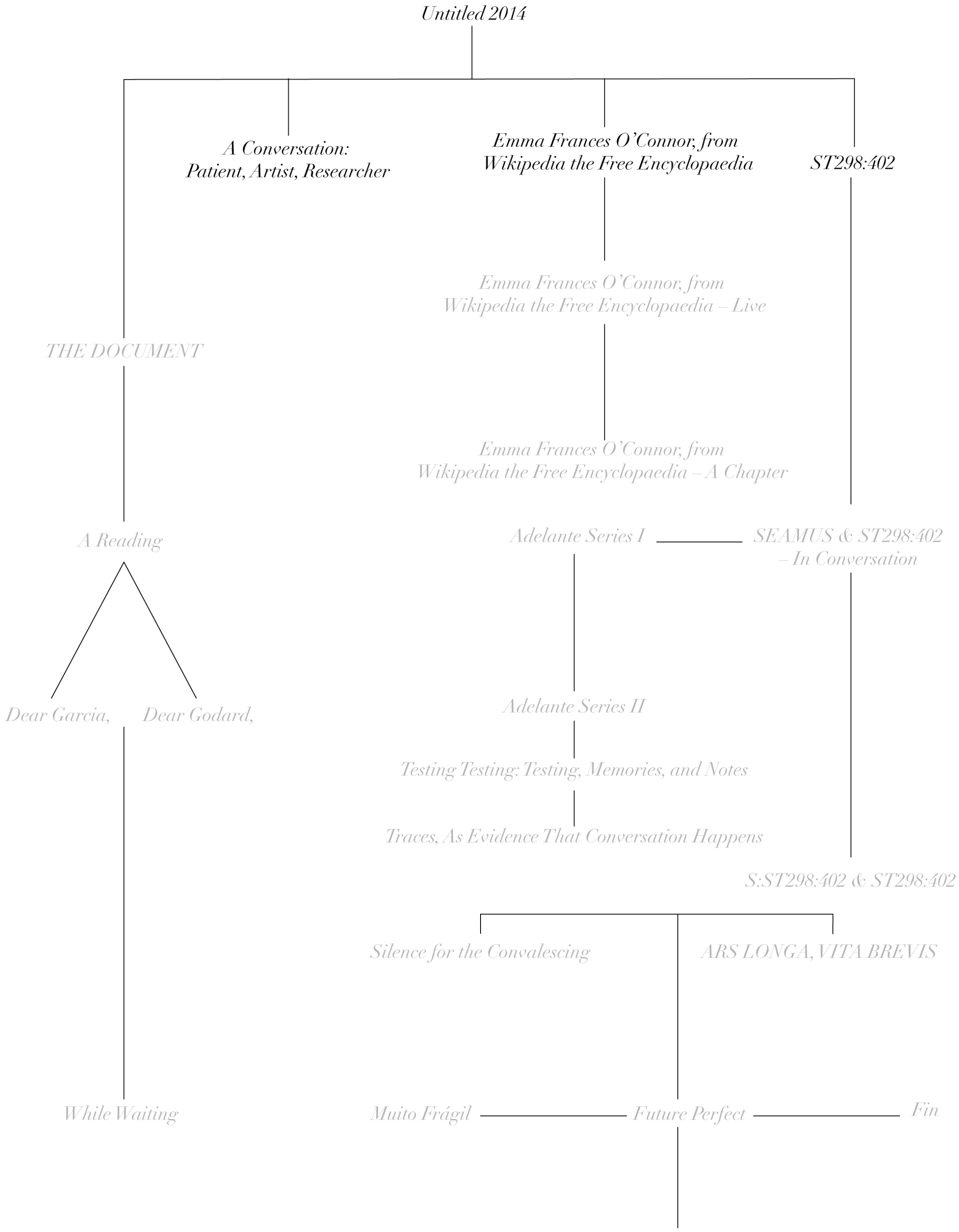
Desire Lines: Looking Afar and Anew, Expanding my Narrative Resources

In the third chapter, I present a detailed reading of and commentary on Jean-Luc Godard's *Passion* (1982) and *Scénario du film 'Passion'* (1982), and Dora García's *The Joycean Society* (2013), each selected for its potential to address the problems with patient narrative. I focus on the mechanics of the works and narrative processes, identifying their elements and analysing how these function in the work, to facilitate my discovery of aspects, categories, and devices that I explore through constructing my own patient narrative. My discussion is limited to these works; looking in a direction other than towards those works already attending to illness, enabled something new to be brought back into the field. In this way, and through maintaining a focus on narrative strategies, I expanded my narrative resources. Choosing only a limited number of works allowed me to look in close detail. Looking away from illness also gave me some respite and reinvigoration from a preceding extended focus on illness.

Patient Narrative Re-imagined

My concluding chapter summarises and reflects on the research findings in relation to my research aims and the wider context and genre of genetic patient narrative. I write about the specific insights delivered by my readings of Godard's *Passion* and *Scénario du film 'Passion'*, and García's *The Joycean Society* (2013), for the research enquiry, creative practice, and thinking about narrative form and function. To demonstrate that the art practice is autoethnographic, I refer back to my body of art practice to consider the specific insights delivered by the art practice in making connections between individual patient experience and of genetic medicine and wider culture/society. I elaborate on the claim that art can critique and have an impact on the expectation and form of the patient narrative, as promoted and experienced in medical profession contexts, through a discussion of my own work to reflect on exactly what art might offer in a clinical context that opens up medical discourse and patient experience. I revisit the current debate in the medical humanities regarding the definition of patient narrative, positioning my work therein. I suggest implications for the work, and consider how the work will be developed to have practical application in the field of patient narratives. I acknowledge weaknesses in the work, suggesting how they might be improved in the proposal for future work. A final *Pé de Grue* diagram precedes this chapter; while closing the thesis, its acknowledgement of new works in development suggests also an opening.

PÉ DE GRUE —— PEDIGREE I



PÈ DE GRUE ———— PEDIGREE I

Untitled 2014 — A Conversation: Patient, Artist, Researcher —
ST298: 402 — Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia

Untitled 2014

Untitled 2014 is a series of 5 x 4 inch index cards. Presented in a clear plastic box, the cards may be flicked through and reordered. On each card there is a fragment of narrative in the form of a screenplay: A setting, a character, dialogue, or an image is revealed by writing in blue-black ink, photographic images, and small objects. Each card is not clearly part of a larger, linear narrative whole. I question the imperative to find meaning. As I explore meaning as the goal of patient narrative, an interesting paradox arises in making meaning out of meaninglessness. I question what happens if one accepts that illness is inherently meaningless: what is gained, and what is lost by its presentation and reception as incoherence and meaninglessness. However, in so doing, *Untitled 2014* also illuminates the perniciousness of narrative. When making *Untitled 2014*, I was caught between a desire for narrative on the one hand – with its familiarity, linearity, cause and effect relations, offer of the possibility of transformation, and order – and an acknowledgement of its fallibility on the other.[25] Realising the pull of narrative – as our minds search for meaning and posit causal relations – I began to see the challenge of disrupting narrative as potentially insurmountable. I realised how difficult it is to shake off narrative: the more fragmented the presentation of work, the stronger the will to make a meaningful narrative.

Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia

Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia is a twenty-minute performative lecture, structured around a Wikipedia entry scripted and read by me. The audience simultaneously views a video in which the construction of the entry, the

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[25] This is echoed in all my narrative creation, as I too want a happy ending.

processes of its being edited, authored, co-authored, constructed, and co-constructed, are revealed. The work responds to ideas stemming from Strawson's 'episodic' – resisting a sense of wholeness, revealing a constructed narrative open to revision. I was thinking about closure and did not want the work to offer a final resolution, preferring to leave open future possibilities for further revision and multiple restructurings. *Emma Frances O'Connor* was made for a conference on storytelling held in Portugal,[26] and as I think my stomach travelled to Portugal for analysis, the work responds to Frank's quest narrative. I was thinking about emplotment and the implication of causal relations between events – constitutive and supplementary – in narrative.

A Conversation: Patient, Artist, Researcher

A Conversation: Patient, Artist, Researcher is a performative lecture consisting of three elements: a screen recording that captures the construction of a scripted interview with me as patient, artist, and researcher; an audio recording of the scripted interview; and a live reading by me. The work explores institutional and cultural biases towards certain narrative structures through the analysis of the article I wrote for the *Independent* newspaper, drawing on an email exchange between the features editor and me.[27] I was thinking about the different forms that patient narrative take, specifically the use of interview to collect patient narratives.

ST298:402

ST298:402 is a 14 minute 37 second film with sound. Over a year I filmed daily, documenting the journey of my research, recording aspects of my life. These experimental, narrative sketches constitute the material, ranging from handheld footage to longer tripod-held shots. Editing, I was torn between constructing a coherent narrative and resisting this desire – cutting and combining my footage with no over-

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[26] 5th Global Conference: Storytelling: Global Reflections on Narrative, Inter-Disciplinary.net, Lisbon, Portugal, May 2014.

[27] Please refer to my description of this on pages 32–34.

arching narrative to rule my decision-making. The work responds visually to indeterminacy through the use of blur. I was thinking about my identity as a patient, exploring this through the filming of myself in surfaces with different degrees of opacity and reflectivity. The title of *ST298:402* explores naming and referring as aspects of medical discourse. Using numbers to identify patients is common practice in medical research and raises ethical issues around naming, withholding, and anonymity. My re-appropriation of my patient number raises questions as to my motives: an effort to take control, an attempt to use the tools of anonymity to fight against anonymity, or a scar bravely worn.

Patient Narrative Part I: Taking a History – Patient Narrative Past and Present

A History of Patient Narrative — Biographical Disruption and Narrative Reconstruction — Definition — Arthur Frank's Typology of Illness Narratives — Illness and Metaphor

A History of Patient Narrative

The sociologist Mike Bury begins 'Illness Narratives: Fact or Fiction' with a description of medicine in the seventeenth and eighteenth centuries. In an era without the contemporary technologically advanced tests and procedures of biomedicine, patients' experiences and narratives were indispensable to doctors. Disease was considered as deviation from a 'natural' state, and doctors had to pay careful attention to patients, gathering information about their condition and lives to enable diagnosis and treatment of illness.[28]

The mid- to late nineteenth century saw the advent of biomedicine and the conception of the modern hospital and laboratory. As a consequence, the importance placed on patient experiences by doctors diminished.[29] 'Illness' was separated from its biomedical counterpart 'disease', no longer seen as a deviation from a 'natural' state but as a divergence from the statistically 'normal'.[30]

By the twentieth century, the bio-medical model had become the dominant mode for understanding disease. The role of the expert doctor was to elicit information regarding the objective signs and symptoms of disease for diagnosis and treatment.[31] The separation of the medical model of disease from lay experiences of illness is often cited

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[28] Mike Bury, 'Illness Narratives: Fact or Fiction?', *Sociology of Health and Illness*, 23, 2001, 263–85, p. 265.

[29] Nicholas D. Jewson, 'The Disappearance of the Sick-Man from Medical Cosmology 1770-1870', *Sociology,* 10, 1976, 225–44. Cited in Bury, 'Illness Narratives', p. 266.

[30] Christopher Lawrence, *Medicine in the Making of Modern Britain 1700-1920*, London: Routledge, 1994, p. 45. Cited in Bury, 'Illness Narratives', p. 266.

[31] Bury, 'Illness Narratives', p. 266.

as accounting for a widening of the gap between the lay and professional worlds.[32] Indeed, this process reflected a more general assimilation of other elements of daily life into the professional sphere under conditions of modernity.[33]

In 1948 the World Health Organisation defined health as ‘a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity’,[34] a definition that has not changed.[35] This definition suggests a departure from the earlier conception of disease as deviation from the statistically normal. However, further advances in medicine – characterised by innovations in medical and surgical technologies, treatments, and procedures in the 1940s – saw illness as ‘increasingly sequestrated from everyday life […] so the patients’ suffering was effectively silenced.’[36]

In 1951, medical sociologist Talcott Parsons’ ‘sick role’ assigned social roles, rights, and responsibilities to the sick, exempting them from certain duties while obliging them to get well.[37] Drawing on Parsons’ observation that ‘a core social expectation of being sick is surrendering oneself to the care of a physician’,[38] the sociologist Arthur Frank employs the term ‘narrative surrender’ to describe patients surrendering of personal narrative to the biomedical terms and voices imposed on them.[39]

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[32] Leon Eisenberg, ‘Disease and Illness: Distinctions between Popular and Professional Ideas of Sickness’, *Culture Medicine and Psychiatry,* 1, 1977, 9–23; Eliot Freidson, *Profession of Medicine: A Study in the Sociology of Applied Knowledge,* Chicago, IL: Chicago University Press, 1970. Cited in Bury, ‘Illness Narratives’, p. 265.

[33] Featherstone, Mike, ‘The heroic and the everyday life’, *Theory, Culture and Society,* 9, 1992, 159–82; Anthony Giddens, *Modernity and Self Identity: Tribulations of the Self,* Cambridge: Polity Press, 1991. Cited in Mike Bury, ‘Illness Narratives’, p. 266.

[34] Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

[35] Machteld Huber et al., challenge the WHO definition of health – as complete wellbeing – arguing that, due to the rise of chronic disease, it is not appropriate. They propose the revision of the definition of health, emphasising adaptability and self-management in the face of social, physical, and emotional challenges.

Machteld Huber, André Knottnerus, Lawrence Green, Henriëtte van der Horst, Alejandro R. Jadad, Daan Kromhout, Brian Leonard, Kate Lorig, Maria Isabel Loureiro, Jos W. M. Van der Meer, Paul Schnabel, Richard Smith, Chris Van Weel, Henk Smid, ‘How should we define health’, *British Medical Journal*, 343, 1–3, 2011 <doi: 0.1136/bmj.d4163> [accessed 28 June 2017].

[36] Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics,* Chicago, IL: University of Chicago Press, 1995, p. 6.

[37] Talcott Parsons, *The Social System,* New York, NY: Free Press, 1964 [1951].

[38] Frank, *The Wounded Storyteller*, p. 6.

[39] Frank, *The Wounded Storyteller,* p. 6.

The AIDS pandemic saw an explosion in the production of patient narratives, and by the late twentieth century, it was seen as a distinct literary genre ‘central to the literary branch of medical humanism’.[40] The current field of patient narratives presents a vast source for critical enquiry. The technological developments of the twentieth century produced many ways to construct and report illness.[41] Text-based forms include autobiographical writing, critical essays, novels, memoirs, digital stories, academic articles, fiction, and blogs. Examples of non-linguistic forms are non-representational art, abstract photography or painting, sculpture, film, drawing, and bodily performance. Authors include patients, doctors, family members, and carers. Patient narratives are written for a variety of purposes. They may be written to find meaning, normalising, aestheticising, confessing, validating, pleasing others, obtaining financial rewards, healing, and communicating. Patient narratives may provide access to the subjective experiences of illness; accommodate changes in identity that might result from illness; and challenge master narratives – reclaiming the ‘patient voice’. They may make meaning from illness, exert control, warrant decision-making, and propel policy change.[42] The emphasis on patient narratives stems from high levels of chronic illness, changes in morbidity patterns, the expansion of information about illness and disease, public debates about the effectiveness of medicine, a saturation of knowledge on the Internet – as well as other cultural, historical, medical, social, and political reasons.

Biographical Disruption and Narrative Reconstruction

The sociologist Kohler Riessman writes that illness ‘interrupts lives that many individuals assume will be continuous, ordered, sequential [...] the interruption of life by a chronic illness must be accounted for, placed in context of the life before and after, at least by Westerners embedded in cultures that privilege modernist notions of a

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[40] Jurecic, *Illness as Narrative*, p. 2.

[41] Jurecic, *Illness as Narrative,* p. 3.

[42] Jon F. Nussbaum, Roxanne Parrott, and Teresa L. Thompson (eds), *The Routledge Handbook of Health Communication*, 2nd edition, London: Routledge, 2011, p. 42.

continuous "self".'[43] Bury's work on 'biographical disruption' – the disruptive impact of illness on 'normal' life and biographical identity – and Gareth Williams' work on 'narrative reconstruction' – the reworking of biographical context to make meaning from illness – are commonly cited in the literature on patient narrative.[44]

Williams' 'narrative reconstruction' requires the use of emplotment – a term employed by the historian Hayden White to refer to the process by which events and series of events are transformed into stories through the identification of cause and effect.[45] Emplotment was first proposed by the Russian Formalists and later developed by the Structuralists as the main constituent of narrative. Languages professor Gerald J. Prince writes that not 'everything is narrative' rather 'everything' may be part of a narrative'.[46] Sjoerd-Jeroen Moenandar, professor in narrative communication, writes that 'we experience reality and then we construct a story out of this experience'.[47] White writes that events and series of events in themselves do not comprise 'a story manifestly finished and complete', concluding: 'we do not live stories, even if we give our lives meaning by retrospectively casting them in the form of stories'.[48] He emphasises the importance of the relations between the different events of which the narrative is constructed: they 'are not [...] immanent in the events themselves'.[49] Emplotment is not dictated by experiences narrated, but is applied to those experiences.[50]

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[43] Catherine Kohler Riessman, 'Illness Narratives: Positioned Identities', Invited Annual Lecture, Health Communication Research Centre, Cardiff University, May 2002, p. 8 <http://www.cardiff.ac.uk/encap/resources/HCRC-narratives.pdf> [accessed 28 June 2017].

[44] Bury, 'Illness Narratives', pp. 263–85.

[45] Hayden White, *The Content of the Form: Narrative Discourse and Historical Representation,* Baltimore, MD: John Hopkins University Press, 1987. Cited in H. Porter Abbott, *The Cambridge Introduction to Narrative,* Cambridge: Cambridge University Press, 2002, p. 155.

[46] Gerald Prince, 'Revisiting Narrativity' in *Transcending Boundaries: Narratology in Context,* edited by Walter Grünzweig and Andreas Solbach, Tübingen: Gunter Narr Verlag, 1999, pp. 43–51 [*Grenzüberschreitungen. Narratologie im Kontext*]. Cited in Sjoerd-Jeroen Moenandar, 'Introduction', in *Stories of Becoming: Using Storytelling for Research, Counselling and Education,* edited by Sjoerd-Jeroen Moenandar and Lynn Wood, Nijmegen: Campus Orleon, 2017, pp. vii–xxviii, p. ix.

[47] Sjoerd-Jeroen Moenandar, 'Introduction', in *Stories of Becoming: Using Storytelling for Research, Counselling and Education,* edited by Sjoerd-Jeroen Moenandar and Lynn Wood, Nijmegen: Campus Orleon, 2017, pp. vii–xxviii, p. ix.

[48] Hayden White, 'The Historical Text as Literary Artefact', in *The Norton Anthology of Theory & Criticism,* edited by Vincent B. Leitch, New York & London: Norton, 2010, 1536–1553, p. 1538 [Clio: An Interdisciplinary Journal of Literature, History, and the Philosophy of History, 1974, 3, pp. 277-303].

[49] White, 'The Historical Text as Literary Artefact', in *The Norton Anthology of Theory & Criticism,* p. 1548.

[50] Moenandar, 'Introduction', in *Stories of Becoming,* p. xii.

For Frank (and others) storytelling is the transformative vehicle by which the ill person, having undergone 'biographical disruption', might begin 'narrative reconstruction', and thus have agency and heal. Frank, having suffered illness, writes that *The Wounded Storyteller* was 'put together out of my need to make sense of my own survival [...] in a world that does not immediately make sense'. [51] The medical humanist Claire Charlotte McKechnie writes that trauma engenders the desire to tell stories.[52]

Definition

Problematising narrative, the medical humanist Angela Woods in 'The limits of narrative: provocations for the medical humanities' calls for a 'sophisticated account of the genre' of patient narrative.[53] However, since a patient narrative is constructed at a particular time in life, for specified purposes and under certain conditions, influenced by medical discourse as well as socio-political, economic, and cultural forces, the genre is hard to navigate.[54]

Patient narrative, although pervasive in the literature on health and commonly held to be understood by health professionals, has no agreed definition. In *The Cambridge Introduction to Narrative,* without referring to patient narrative, English Professor H. Porter Abbott writes that narrative, in its most simple iteration, is 'the representation of an event or series of events'.[55] Abbott makes three essential distinctions: 'narrative is the representation of events, consisting of story and narrative discourse; story is an event or sequence of events; and narrative discourse is those events as represented'.[56]

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[51] Frank, *The Wounded Storyteller,* p. xiii.

[52] Claire Charlotte McKechnie, 'Anxieties of communication: The limits of narrative in the medical humanities', *Medical Humanities,* 40, 2, 2014, 119–24, p. 122.

[53] Angela Woods, 'The Limits of Narrative: Provocations for the Medical Humanities', *Medical Humanities,* 37, 2011, 73–8, p. 74.

[54] If a more comprehensive account of the genre is to be established, the circumstances and contexts in which patient narratives are created and received must be made explicit.

[55] H. Porter Abbott, *The Cambridge Introduction to Narrative,* Cambridge: Cambridge University Press, 2002, p. 13.

[56] Abbott, *The Cambridge Introduction to Narrative,* p. 19.

Story is always mediated and constructed by narrative discourse.[57] Thus, story seems to pre-exist narrative and *vice versa*.[58] Life, according to Abbott, is the seed ground for narrative.[59] We know about events in lives as they are recounted in narrative – which inflects the stories it tells.[60]

The narrative theorist Jerome Bruner writes that there is no such thing as 'life itself', that narrative imitates life, life imitates narrative, and that life is the same kind of construction of the imagination as narrative. He writes: 'we seem to have no better way of 'describing lived time' save in the form of narrative'.[61]

Abbott acknowledges that for some, narrative requires at least two events; for others, it is necessary that these events are causally related – Bal, Bordwell, and Richardson, *int. al*. Abbott adopts a minimal definition so as not to be restrictive in his view of the field[62] – so that he may consider subsets of narrative extending from this definition.[63] This allows Abbott to engage with what he considers to be the most vital and interesting aspects of the field: 'the complex transaction that involves events, their manner of representation (whether by narrator, actor, paint, or other means), and the audience'.[64]

While acknowledging that definitions proliferate, most notably in narratology, Frank writes that insights gleaned from these definitions reveal only a part of what stories are.[65] Rather, in his work on Dialogical Narrative Analysis (following his work on typologies of illness narratives), he proposes that stories may be understood in three ways: on a horizontal axis, a vertical axis, and from the perspective of a child.[66] The

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[57] Abbott, *The Cambridge Introduction to Narrative*, p. 20.

[58] Abbott, *The Cambridge Introduction to Narrative*, p. 36.

[59] Ibid.

[60] Abbott, *The Cambridge Introduction to Narrative*, p. 37.

[61] Jerome Bruner, 'Life as Narrative', *Social Research*, 54, 1987, 11–32, p. 12.

[62] Abbott, *The Cambridge Introduction to Narrative*, p. 13.

[63] Abbott, *The Cambridge Introduction to Narrative*, p. 14.

[64] Abbott, *The Cambridge Introduction to Narrative*, p. 15.

[65] Arthur W. Frank, 'Practicing Dialogical Narrative Analysis', in *Varieties of Narrative Analysis*, edited by James A. Holstein and Jaber F. Gubrium, Los Angeles and London: Sage, 2012, p. 42.

[66] Frank, 'Practicing Dialogical Narrative Analysis', p. 42.

first draws on the work of the sociolinguist William Labov, showing stories as unfolding in real time, exhibiting the following stages: abstraction (the story is introduced and contextualised in a genre), complicating action, resolution, and evaluation.[67] Frank employs a vertical dimension to differentiate stories from other forms. This vertical dimension includes: character, point of view, genre, suspense, and most importantly for Frank, the imagination – the impact of which, he claims, is that stories 'have their distinctive effects – whether to instruct, to explain oneself, to enrol others in a cause, or simply to entertain […]'.[68] As a means of knowing whether a sufficient number of these elements have been employed so as to constitute a story, Frank proposes the 'bedtime test' – whereby one simply asks if a child is satisfied that what s/he hears is a story. He maintains that 'what a story is should remain fuzzy at the boundaries',[69] noting that 'a story always exceeds the particular language in which it is told'.[70]

Arthur Frank's Typology of Narratives

The medical humanist Anne Hunsaker Hawkins writes that established genres and narrative strategies are used to reconfigure lives and illness experiences in culturally recognisable and acceptable forms.[71] Frank, while stressing the singularity of stories, writes that all stories rely on a limited collection of narrative resources – a 'commonly shared stock of narrative resources that are available to represent what become people's experiences'.[72] A story is never completely one's own story; rather it is 'composed from fragments of previous stories, artfully rearranged but never original'.[73] Frank writes that 'humans are able to express ourselves only because so many stories exist for us to adapt, and these stories shape whatever sense we have of ourselves. […] Humans' very

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[67] Ibid.

[68] Ibid.

[69] Ibid.

[70] Frank, 'Practicing Dialogical Narrative Analysis', p. 43.

[71] Anne Hawkins, *Reconstructing Illness: Studies in Pathography,* West Lafayette, IN: Purdue University Press, 1993. Cited in Lars-Christer Hyden, 'Medicine and Narrative', in *Routledge Encyclopaedia of Narrative Theory,* edited by David Herman, Manfred Jahn, and Marie-Laure Ryan, Abingdon: Routledge, 2005, p. 295.

[72] Frank, 'Practicing Dialogical Narrative Analysis', p. 40.

[73] Frank, 'Practicing Dialogical Narrative Analysis', p. 35.

real sense of selfhood is constrained by the resources we have available to tell our own story…'.[74] With reference to published memoirs, Frank concedes that 'some memoirs rightly claim to expand this stock of resources'.[75]

In his work on first person illness narratives, Frank – motivated by a desire to help listeners attend more closely to stories told by the ill – proposes a typology of illness narrative.[76] Following extensive narrative analysis, he reports that three core narrative types are visible in illness stories, defining type as 'the most general storyline that can be recognised underlying the plot and tensions of particular stories'.[77] These are the restitution narrative, the chaos narrative, and the quest narrative.[78] Although Frank discusses these separately, he writes that the majority of illness stories combine elements of all three types.[79]

In the restitution narrative, the ill person begins well, becomes sick, and – thanks to treatment – is restored to a satisfactory level of health. This expectation of restitution relates to Parsons' sick role, where a return to reasonable health is assumed.[80] Medicine is the protagonist – endowed with agency to heal – and restitution narratives commonly draw on readily available medical terms as resources.[81]

The narrative case study of two sisters who have the CDH1 genetic mutation, featured on Cambridge University Hospitals website for familial gastric cancer, exemplifies

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[74] Ibid.

[75] Arthur W. Frank, 'Trickster Narrates the Balance of Health', in *Communicating for Social Impact: Engaging Theory, Research, and Pedagogy,* edited by Lynn M. Harter, Mohan J. Dutta, & Courtney E. Cole, Cresskill, NJ: Hampton Press, 2009, p. 21–31. Cited in Frank, 'Practicing Dialogical Narrative Analysis', p. 40.

[76] Frank, *The Wounded Storyteller,* p. 76.

[77] Frank, *The Wounded Storyteller*, p.75.

[78] Ibid.

[79] Other typologies of illness exist classifying the ways patients narrate their illnesses: Robinson classifies lives in illness narratives as stable, progressive, and regressive (Ian Robinson, 'Personal narratives, social careers and medical courses: Analysing life trajectories in autobiographies of people with multiple sclerosis', *Social Science and Medicine,* 30, 1990, 1173–86). Lars-Christer Hyden approaches the formal aspects of narrative, basing his system on the relation between the narrator, narrative, and illness Lars-Christer Hyden, 'Illness and Narrative', *Sociology of Health & Illness,* 19, 1, 1997, 48–69). It would have been impossible, given the limits of time, to look at each existing system of classification. Moreover, I deemed it unnecessary given the prominence of Frank's typology in the field.

[80] Frank, *The Wounded Storyteller,* pp. 82–3.

[81] Arthur W. Frank, 'Practicing Dialogical Narrative Analysis', p. 47.

Frank's restitution narrative.[82] I discovered this narrative visiting the website as a patient, checking for updates on my condition. It is a lengthy piece and features photographs of Ruth and Lisa Bendle, Professor Carlos Caldas and Dr Rebecca Fitzgerald (their geneticists), and Richard Hardwick (their surgeon).

Word choice and frequency say something of the text and the writer. The most frequent content word in the text is *cancer*, written fifteen times. The second most common is *sisters*, occurring thirteen times. *Surgery* is written twelve times. *Stomachs* (plural) ten, and *stomach* (singular) eight. The words *disease* and *research* are written seven times. *Operation*, and *care,* six; *hospital,* five. *Time* is written twice. *Positive* is written once, in a quote – collocated with *test* – by Rebecca Fitzerald: 'It's a big decision for families to take genetic testing for the faulty gene. They have to be able to face the consequences of a positive test.'

The piece is punctuated with quotations. First, we read the words of Ruth and Lisa Bendle's surgeon Mr Richard Hardwick, next their geneticist Dr Rebecca Fitzgerald, Carlos Caldas, Professor of Cancer Medicine follows, then Nicola Grehan, Research Nurse, specialist nurses Ben Smith, Mhairri Duxbury, and Linda Bycroft, Heather Jones and Mary-Anne Coleman, radiographers… **'…it was both unique and very challenging.'** An un-authored quote appears in bold.

Dr Kevin Gunning, consultant anaesthetist, Edna Kouzel, team leader in theatres five and six, Moira Howley, Junior Sister in the Intermediate Dependency Area, Dr Vicki Save, Consultant Histopathologist and Lead GI Pathologist, Sam Grimes, Chief Oncology Dietitian (sic). In the last lines, we hear from Ruth Bendle, patient: 'We owe our lives to this new technology. It's unbelievable really – and astonishing to think that you don't actually need a stomach to live.' Lisa Bendle, patient: 'It's a new start for us, a new life.'

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[82] Cambridge University Hospitals, Familial Gastric Cancer Study <http://www.cuh.org.uk/familial-gastric-cancer-study/case-study> [accessed 28 June 2017].

The influence of medical discourse is heavy and the text exemplifies Frank's restitution narrative type. Indeed, in the last lines we read Ruth saying that she owes her life to medical technology, and Lisa that she is experiencing a new start, a new life, thanks to the medical treatment she has received.

This narrative case study seems to be written to inform patients and health professionals about the team of medical practitioners involved in the treatment of Lisa and Ruth. The piece includes several quotes from the medics involved in their care, offering a summary of their contact with Lisa and Ruth, their evaluation of Lisa and Ruth's progress, as well as their own perspectives on how Lisa and Ruth must have been feeling. As a reader, I feel that the team has been very attentive – that Lisa and Ruth must have felt very cared for. Perhaps the intention is to ensure that prospective patients feel reassured. However, as a patient, I also feel a sense of guilt that such an incredible amount of resources is involved in genetic testing and preventative surgery.

Although the author is unidentified, there are many characters drawn from the medical profession who cast Lisa and Ruth's experience of illness in a positive light. What is lacking are Lisa and Ruth's voices – they clearly do not author their narrative case. Its inclusion demonstrates a way in which the patient voice is commonly presented: Self-authored genetic patient narratives about the CDH1 genetic mutation, on websites other than blogs, are rare.

In the chaos narrative, the ill person – the protagonist – faces multiple problems confounded by illness. All attempts to heal are futile. The chaos narrative lacks plot and a coherent narrative structure is not imposed on the patients' fragmentary experiences. Frank suggests that chaos narratives are anti-narrative 'in the sense that while one thing happens after another, none of it goes anywhere'.[83] Franks cites a lack of available narrative resources as causative of this failure to narrate.[84] Chaos narratives are rarely visible.

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[83] Frank, 'Practicing Dialogical Narrative Analysis', p. 47.

[84] Frank, 'Practicing Dialogical Narrative Analysis', p. 48.

Having employed the biblical figure of Job – [who] 'with his new family and cattle, basks in God's graciousness'[85] – to exemplify the restitution plot, which reassures with its promise of a happy ending, Frank adapts the actions of Job in a manner which he writes is a chaos story. In Frank's adaptation, Job takes his wife's advice, curses God, and dies, which, according to Frank, is (or would be) a chaos narrative. However, the example does not translate into modern, secular society as Frank intends. In the biblical story, God puts Job to the test; when Job is unwilling to renounce God, God rewards him. As an illness narrative, this would surely entail that modern medicine not only supplies the cure to illness, but is the cause also.

Frank features 'the voice of chaos' through Nancy's words, captured in an interview excerpt reported by sociology professor Kathy Charmaz.[86] Nancy, writes Frank, has a chronic illness and family problems.

> And if I'm trying to get dinner ready and I'm already feeling bad, she's in front of the refrigerator. Then she goes to put her hand on the stove and I got the fire on. And then she's in front of the microwave and then she's in front of the silverware drawer. And – and if I send her out she gets mad at me. And then it's awful. That's when I have a really, a really bad time.[87]

The quest narrative is a monomyth, an archetypal narrative in which heroes are transformed by their journey.[88] The quest narrative hinges on whether the ill person will come to understand the transformative nature of her/his illness. Frank writes that the 'storyteller of quest narratives is most likely to claim to have elaborated the narrative resources available to future ill people – that this elaboration is part of the quest'.[89]

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[85] Frank, 'Practicing Dialogical Narrative Analysis', p. 97.

[86] Frank, *The Wounded Storyteller,* p. 99.

[87] Kathy Charmaz, *Good Days, Bad Days: The Self in Chronic Illness and Time*, Berkeley, CA: University of California Press, 1991, p. 173. Cited in Frank, *The Wounded Storyteller*, p. 99.

[88] Frank, 'Practicing Dialogical Narrative Analysis', p. 47.

[89] Ibid.

Running against genes – a patient story on *Patient Voices* website[90] – exemplifies Frank's quest narrative. It is 1 minute 56 seconds long, consisting of a voiceover narrative, a series of still images and photographs, and introductory music. I am curious if the photographs are of the author and her family; I wonder if the voice-over narration is that of the story's author – who remains anonymous despite photographs, which through their position might be assumed to be of the patient.

The story begins with an image of a hand holding two pills against a background of green grass. The first person voiceover narrates how the narrator (perhaps also the author) has always hated taking pills. The narrator reveals how she has to 'get along with' taking pills because of her genes. This is accompanied by an image of genes, which the narrator comments 'actually look quite beautiful'. Next is a black and white photograph of a young man. As the narrator speaks of the genes she inherited from her father, I assume he is the man in the photograph. The narrator speaks of how her father, who always took care of himself, suffered because of his genes and 'now he is a vegetable'.[91] We see a family portrait and the narrator speaks of how, since her father is part of her, she tries to 'outwit her genes'. Following this, we see a picture of what appear to be genes, and then a photograph of a pair of trainers. The narrator speaks of taking a pill each day of the year and running – the two things she does to 'outwit her genes'.

The narrator thanks her genes for allowing her to experience the nearby beech forest all year round – a photograph of a path through a green forest accompanies this. The narrator elaborates on these positive effects of her genes, speaking of how she has seen the spring flowers, can now recognise the sound of a woodpecker, and enjoys greeting friendly, happy people on her runs. She ends: 'so I'm full of life and hope for the future, what a moving trip' – employing the trope of the journey, exemplifying the quest

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[90] Patient Voices, *Pilgrim Projects*, 2015 <http://www.patientvoices.org.uk/flv/0411pv384.htm> [accessed 28 June 2017]. Patient Voices is an organisation that collects patients' stories and digitises them for use in medical training to stimulate learning and improve healthcare. Patient Voices has been awarded the British Medical Journal for Excellence in Healthcare Education.

[91] The origins of this usage are not clear, however, this use of 'vegetable' may derive from the medical terms persistent and permanent vegetative states. Regardless, the usage cited is seen as derogatory by many.

narrative. Illness is viewed as transformative and the narrator says that she now experiences life, particularly nature, in a more profound way. The narrator, rather than medicine, is instated as hero.

Illness and Metaphor

Heroic metaphors, journey metaphors, those drawn from warfare, have become accepted, if also contested, ways of talking about illnesses and survivorship.[92]

Together we will beat cancer

As a patient at two HDGC workshops at Cambridge University Hospital in 2014 and 2016, I sat in a lecture theatre with ‘Together we will beat cancer’ written on the walls, wondering what effects this implication of the battle metaphor might have on people with experience of genetic diagnosis and preventative surgery. Post-gastrectomy it is unlikely that I will get stomach cancer, but am I cured? Have I beaten cancer? At times, when fatigued or worried about weight loss, or when I try to understand the risks associated with breast and bowel cancer, or when I am in extraordinary pain due to bowel adhesions, it does not feel like it.[93]

Acknowledging that metaphors of a journey and metaphors of violence are both used in empowering and disempowering ways, Elena Semino, Professor in Linguistics and

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[92] Carola Skott, researcher in health and care sciences, writes that the word *cancer* is a metaphor, traceable to Hippocrates who ‘likened the long bulky veins radiating from lumps in the breast to crabs (*carcinoma* in Greek, *cancer* in Latin)’. Carola Skott, ‘Expressive Metaphors in Cancer Narratives’, *Cancer Nursing*, 25, 3, 2002, 230–35, p. 231.

[93] As registered charity, Cancer Research UK is reliant on funding. There is suggestion that metaphors of battle motivate groups to act, perhaps explaining their use in fundraising campaigns. See: Misha Gajewski, *May I take your metaphor? – how we talk about cancer,* Science Blog, Cancer Research UK, 28 September 2015 <http://scienceblog.cancerresearchuk.org/2015/09/28/may-i-take-your-metaphor-how-we-talk-about-cancer/> [accessed 28 June 2017].

English Language, writes that the 2007 NHS Cancer Reform Strategy[94] avoids metaphors of violence in favour of the journey (a feature of the quest narrative).[95]

In *The Story of Pain,* Joanna Bourke seeks to understand how people in the past suffered by attending to the language that they used as clues to unspoken meaning.[96] Bourke turns to the words of Peter Mere Latham – 'almost all language is figurative … Inflammation and fever contain the figures of burning and boiling … […] Is it not true that the popularly prevalent notion of treating inflammations and fevers turns to the purposes of extinguishing and refrigerating?'[97] – to argue that the metaphors chosen to communicate pain impact not only on the manner in which pain is felt, but also treated.

Bourke explores the history of war metaphors in illness, exemplifying this with John Donne's *Devotions on Emergent Occasions* (1624) in which illness is likened to armed conflict between kingdoms.[98] Bourke draws a correlation between the proliferation in metaphors of war to represent illness and the creation of germ theory of disease in the 1860s and 1870s.[99] In the twentieth century, metaphorical use of vocabulary drawn from war is explained by a militarisation of British and American societies and the pharmaceutical development of analgesics (painkillers).[100] Bourke explores metaphors for pain drawn from railway accidents, electricity, torture, nature, and religion.[101] She cites three reasons to account for fluctuations in the use and type of metaphors for pain: ideological shifts, changes in conceptions of the physiological body, and developments

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[94] NHS, *NHS Cancer Reform Strategy,* 3rd December 2007 <http://www.nhs.uk/NHSEngland/NSF/Documents/Cancer%20Reform%20Strategy.pdf> [accessed 28 June 2017].

[95] Elena Semino, Zsófia Demjén, Jane Demmen, Veronika Koller, Sheila Payne, Andrew Hardie, and Paul Rayson, 'The online use of Violence and Journey metaphors by patients with cancer, as compared with health professionals: a mixed methods study', *British Medical Journal Supportive & Palliative Care,* 7, 2017, 60–6, pp. 60, 62–3.

[96] Joanna Bourke, *The Story of Pain: From Prayer to Painkillers,* Oxford: Oxford University Press, 2014, pp. 53, 56.

[97] Peter Mere Latham, 'General Remarks on the Practice of Medicine', *British Medical Journal,* 1862, p. 26. Cited in Bourke, *The Story of Pain,* p. 53.

[98] John Donne, *Devotions on Emergent Occasions,* edited by Anthony Raspa, Montreal: McGill–Queen's University Press, 1975, pp. 52–4 [*Devotions Upon Emergent Occasions, and Several Steps in My Sickness,* 1624]. Cited in Bourke, *The Story of Pain,* p. 74.

[99] Bourke, *The Story of Pain*, p. 74.

[100] Bourke, *The Story of Pain*, p. 75.

[101] Bourke, *The Story of Pain,* pp. 76–9.

in the external environment.[102] Bourke argues that metaphoric language cannot be avoided: sufferers employ figurative language to impose or communicate order onto their experience and to invoke sympathy.[103]

She writes that metaphor is analogic, founded on visual and spatiotemporal correspondences with sensation.[104] My patient experience involves sensation in so far as pain plays a part in my patient experience – in my recovery from surgery, resulting complications, and sporadic discomfort – and figurative language proves useful. Yet figurative language is less useful in communicating my everyday patient experience. Perhaps this is due to a lack of feeling – I did not feel anything before receiving my diagnosis – or perhaps it is due to a language not yet developed to attend to that of genetic medicine, which in my experience uses numbers rather than words. Susan Sontag, in *Illness As Metaphor,* writes that such radical cancer metaphors of aggressive warfare are a crass invitation to oversimplify something so complex. However, as understanding of cancer and its treatment develops, Sontag writes that the language of cancer will evolve, until finally, once de-mythicised, cancer as a metaphor will become obsolete 'long before the problems it has reflected so persuasively will be resolved'.[105]

Perhaps metaphor, unlike narrative, is a form of naming. In *The Poetics* Aristotle writes of metaphor 'as giving the thing a name that belongs to something else'.[106] The philosopher Friedrich Nietzsche referred to his pain as his dog: '[…] just as faithful, just as obtrusive and shameless, just as entertaining, just as clever as any other dog'.[107] My grandfather referred to our genetic condition as 'the bug'. Both instances conceive their

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[102] Bourke, *The Story of Pain*, p. 66.

[103] Bourke, *The Story of Pain,* pp. 55, 58.

[104] Bourke, *The Story of Pain*, p. 58.

[105] Susan Sontag, *Illness As Metaphor & Aids and its Metaphors,* London: Penguin, 1991 [*Illness As Metaphor,* New York: Farrar Straus & Giroux, 1978; *AIDS and its Metaphors,* New York: Farrar Straus & Giroux, 1989] p. 87.

[106] *Aristotle on the Art of Poetry,* translated by Ingram Bywater, Oxford: Oxford University Press, 1909, p. 63. Cited in Bourke, *The Story of Pain,* p. 54.

[107] Friedrich Nietzsche, *The Gay Science,* translated by Walter Kaufmann, New York, NY: Vintage Books, 1974, pp. 249–50 [*Die Fröhliche Wissenschaft,* Chemnitz: Ernst von Schmeistner Verlag, 1882]. Cited in Bourke, *The Story of Pain,* p. 61.

object as a separate entity, whether within or external to the body – a tactic, which Bourke writes, may enable the speaker to exert control over a given entity.[108]

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[108] Bourke, *The Story of Pain,* pp. 61–62.

Patient Narrative Part II: A Critique of Dominant Modes of Patient Narrative

Linearity — Transformation — Patient Narratives as Healing —
Patient Narratives as Data — The Imposition of Narrative — In Summary

Linearity

Biographical accounts of illness, which presuppose a particular understanding of identity, dominate the current field of patient narrative. Woods draws on the philosopher Galen Strawson's 'episodic' self and identity – 'that one does not figure oneself, considered as a self, as something that was there in the (further) past and will be there in the (further) future'[109] – to raise the objection that narrative as a mode of self-expression promotes a particular model of self:

> as an agentic, authentic, autonomous storyteller; as somebody with a unique insight into an essentially private and emotionally rich inner world; as someone who possesses a drive for storytelling, and whose stories reflect and reaffirm a sense of enduring, individual identity.[110]

The insistence on a fixed, linear understanding of patient narrative is remarkable. In other disciplines, notably literary criticism, it has long been accepted that post-modernism and deconstruction have undone linear accounts.[111] Despite claiming an interdisciplinary perspective, the medical humanities have faced criticism for their neglect of diverse disciplinary approaches that would better elucidate narratives of health.[112] Keir Waddington and Martin Willis, working across the disciplines of literature and science, argue that the debate in the medical humanities should acknowledge 'that narratives need not be linear, they need not be structured as

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[109] Galen Strawson, 'Against Narrativity,' *Ratio,* 17, 2004, 428–52, p. 430.

[110] Woods, 'The Limits of Narrative', p. 74.

[111] While I will draw on literary criticism, this project is about patient narrative specifically.

[112] Keir Waddington and Martin Willis, 'Introduction: Rethinking Illness Narratives', *Journal of Literature and Science*, 6, 1, 2013, p. iv–v <http://www.literatureandscience.org/wp-content/uploads/2013/09/JLS-6.1-Complete-Issue.pdf> [accessed 28 June 2017].

traditional story-telling forms (as dramas, poetries, and prose), nor need they offer logic, coherence, or temporal movement'.[113] They write that this neglect 'is a result of a very limited set of influential critics (and works of critical insight) whose own specialisms are not those of the humanities but instead come from the sociological and health disciplines'.[114]

Transformation

The quest narrative – with its insistence on transformation – is often referred to as the ideal patient narrative. Variations of Frank's quest narrative have been adopted as the ideal illness narrative and now populate entrepreneurial and patient advocacy websites aimed at facilitating the telling and hearing of patients' stories.[115]

I question why such institutional and cultural biases towards quest narrative structures arise and persist in society. I explore this through the analysis of *Life without my stomach*, my non-fiction feature article, first published in the lifestyle, health, and families, features section of *The Independent* newspaper on Saturday 17 September 2011, and now available online.[116] Despite writing the piece myself, several emails were exchanged between the editor and me, a correspondence that highlights her – and her readership's, on whose behalf she spoke – insistence on positivity, narrative order, chronology, and drama.

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[113] Waddington and Willis, 'Introduction: Rethinking Illness Narratives', p. iv–v <http://www.literatureandscience.org/wp-content/uploads/2013/09/JLS-6.1-Complete-Issue.pdf> [accessed 28 June 2017].

[114] Waddington and Willis, 'Introduction: Rethinking Illness Narratives', p. iv–v <http://www.literatureandscience.org/wp-content/uploads/2013/09/JLS-6.1-Complete-Issue.pdf> [accessed 28 June 2017].

[115] See: No Stomach For Cancer Inc., *No Stomach For Cancer,* 2014 <http://www.nostomachforcancer.org/> [accessed 28 June 2107]; Patient Stories, 2012 <https://www.patientstories.org.uk/>, [accessed 28 June 2107]; Stand up to cancer, 2008-2015, Entertainment Industry Foundation (EIF) < http://www.standup2cancer.org/blog/> [accessed 28 June 2107].; Health Talk Online, Dippex, 2015 < http://healthtalk.org/peoples-experiences/cancer/breast-cancer-women/tamoxifen> [accessed 28 June 2107]; Patient Voices, Pilgrim Projects, 2015 <http://www.patientvoices.org.uk/flv/0411pv384.htm> [accessed 28 June 2017].

[116] Emma O'Connor, 'Life without my stomach', *Independent,* 27 November 2007, Lifestyle, Health and Families, Features section <http://www.independent.co.uk/life-style/health-and-families/features/life-without-my-stomach-5337361.html> [accessed 28 June 2017].

The title – *Life without my stomach* is in bold type, attracting readers' attention – is accompanied by the subtitle, 'Emma O'Connor opted for radical surgery to avoid the risk of getting a deadly cancer. One year on, she's sure she made the right choice', framing my narrative for the reader. Medical information, extraneous to the article, is added at the end of my narrative, revealing the editor's expectation that the readership will not have a complex understanding of medical genetics.

As well as the author and narrator, I am the central character of the article – medicine is another character with agency. I was counselled by the editor to start at the most climatic point and 'flesh it out from there'. This was to gain the reader's attention and, as such, constitutes a simple narrative structure. The beginning is structured with a flashback as I narrate the imagined scene in the operating theatre with a bird's eye view. Word choices connote a science fiction world, dreamlike and removed from reality. My walk to theatre is then recounted.

In the second paragraph, I use simile to describe the feeling of waking up post-surgery, establishing the binaries of reality and dream, sleep and awakening. References to time as I experienced it, included in the first two paragraphs – still, unfolding, unexpectedly, seconds passed, catch-up, remembered, the last few hours – might be read in opposition to later references to abstract time – 'In November…two years…just over a year'. A third notion of time – distinguished from internal time (the sequence of events constituting the plot) by Seymour Chatman as the 'chrono-logic' of narrative – is the time taken for a reader to read the article.[117]

I write about adapting to living without a stomach, my understating of my innards, and the milestones of recovery. I generally present a positive recovery with the exception of one paragraph that addresses the effect of fatigue on my social life and a subsequent hospital readmission with blocked intestines due to adhesions. The article closes with my desires for the future – a trip to South America – and my fears for the future, related

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117 Seymour Chatman, *Coming to Terms: The Rhetoric of Narrative in Fiction and Film,* Ithaca, NY: Cornell University Press, 1990, p. 9. Cited in Abbott, The Cambridge Introduction to Narrative, p. 16.

to complications arising if I am to have children. In the last paragraph I write ‘I believe myself to be very lucky’, ending on a positive note.

Insofar as this article fulfils the criteria I use to define patient narratives, it could be seen to constitute one of my first textual patient narratives. However, the significance of such involvement of finance discourages me from thinking in this way. I saw narrative as a commodity and I wrote with full awareness of this. My purpose in writing was funding a holiday to Spain (after all my ill health limits my capacity to earn money). The article highlights what sells and encompasses an awareness of audience, the buyer.

Although I wrote the article before I began my Ph.D. research, its inclusion shows that previous attempts to reveal my patient experience resulted in a partial re-telling, and that the construction of narrative is influenced by many factors including the context of the reader and the writer. Complexity was sacrificed in favour of a coherent, ordered story and some parts were lost entirely. I neglect to account for the difficulties of living with risk and only allude to the losses in my family that preceded my diagnosis. I omit any reference to feelings of guilt for having survived – mine and my sister’s, who does not have the mutation – and little is written about fear, uncertainty, or the difficult interactions between family members.

Reflection on my participation in a qualitative interview study about HDGC further emphasises the force of institutional and cultural biases to present positive narrative accounts of patient experience. Only when the interviewer’s tape recorder was switched off, did I present my real experience, my debilitating fatigue and misuse of prescription painkillers to overcome this, my pain, etc. Later I was told off-record that I was not alone in having these experiences. This came as a relief – I had felt ashamed of my behaviour – and I suggest there are damaging effects from conforming to triumphant narrative structures. Moreover, my off-record revelation did not feed into HDGC research as data and as such, the story that was relayed to patients and families at an HDGC Information day did not acknowledge this more problematic element of patient experience. While this exclusion was the only way to use information not conceived as research data ethically, it perpetuates a positive narrative telling. As a patient in the audience, I found this difficult. A presentation on fatigue was included in a HDGC workshop at Cambridge University Hospitals in 2016; discussion about painkiller misuse has not yet surfaced.

English Professor Ann Jurecic writes that readers prefer the triumphant narratives commonly at the heart of many personal accounts of risk because by following narrative conventions including closure, they contain the essence of indeterminacy with which they engage.[118] In 'An online resource of digital stories about cancer genetics: Qualitative study of patient preferences and information needs', Rachel Iredale, Lisa Mundy, and Jennifer Hilgart – Institute of Medical Genetics Cardiff University – report patients' preferences for positive stories, commenting that 'people don't want to hear the bad, they want encouragement and support'.[119]

While reading Ben Watt's book *PATIENT*[120] – which charts, in a linear narrative, his period in hospital with a rare autoimmune disease – and simultaneously reading my own patient notes from this period, I remembered the difficult physical and emotional feelings that I experienced in hospital.[121] It was fascinating to read a different account of

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[118] Jurecic, *Illness as Narrative,* p. 24.

[119] Rachel Iredale, Lisa Mundy, and Jennifer Hilgart, 'An online resource of digital stories about cancer genetics: Qualitative study of patient preferences and information needs', *Journal of Medical Internet Research,* 13, 3, 2011 < http://www.jmir.org/2011/3/e78/> [accessed 28 June 2017].

[120] Ben Watt, *PATIENT,* London: Viking, 1996.

[121] See Appendectomies. *ANAMNESIS I* is a text work: a facsimile copy of my patient records relating to my genetic diagnosis and hospital admission for prophylactic gastrectomy. The A4-page photocopies are not assembled in chronological order, but exist as I received them. Each page has two holes punched on the left-hand side and the pages are bound together with a purple treasury tag. The cover bears the title of the work in capitalised bold font, below which is my full name in italics. The cover, unlike all that follow in cheap A4 paper, is printed on transparent tracing paper – little squares of colour at the top suggest a printer test page. In Roland Barthes' *The Preparation of the Novel*, he employs *anamnesis* in his writing on the generative potential of recollection, memory, and its deformation in novels. I later learned that *anamnesis* may refer to remembrance, recollection, and to the medical history of a patient. Reading my medical records, I recalled a time I had not remembered. I realised that some of my time in hospital – when medicated and in theatre – was not available for my recall. As well as the construction of memory, I thought about the existence and status of multiple accounts of events. Thinking and reading about method led me to read about epistemology and ontology. I dug out my old philosophy notes and found it hard to believe I had ever written them for I recalled nothing. I read with interest, from new sources, about anamnesis in Plato's *Meno* – as *a priori* knowledge, recollected from an earlier life. *Anamnesis* is introduced in response to the eristic paradox: that we cannot learn what we know or what we do not know, therefore learning is impossible and inquiry is futile (New World Encyclopaedia, *Anamnesis,* 2016 <http://www.newworldencyclopedia.org/entry/Anamnesis> [accessed 28 June 2017].). Plato defends *anamnesis*, as *a priori* knowledge, unattainable through experience or the senses (New World Encyclopaedia, *Anamnesis,* 2016 <http://www.newworldencyclopedia.org/entry/Anamnesis> [accessed 28 June 2017].

ANAMNESIS II is a text work taking the same form as *ANAMNESIS I. ANAMNESIS II* is an edited collection of photocopied travel ephemera from my quest journeys and textual fragments, written over the course of this doctoral a story I have told since my surgery: On waking I was taken to the recovery unit (a time I remember very clearly) before skipping a planned stay in intensive care, instead being taken onto the ward from which I came. My bypassing intensive care has always been significant to me – I believed and report that this decision was made due to my recovering well. However, my hospital records reveal that that staff in the recovery unit thought it might relieve my anxiety to be in a more familiar environment. I thought that my performance – performance, because I remember being terrified watching the movement of air bubbles through tubes entering into me, which reminded me of the killing off of a character in a popular TV show I watched as a child by an air bubble in an IV line – was good in recovery but read the contrary. Despite the nurses' comments that I was anxious in recovery, it seems I consistently reported positively post-surgery, even denying having experienced shortness of breath.

Although it has been interesting to read the doctors' and nurses' observations with an awareness of how the terms in my notes were marked/unmarked, what strikes me most is how I performed good health – on one occasion even asking for a hairdryer to dry my hair before a family visit so I might look OK – despite often feeling the contrary, as Watt's book reminded me.

I reflect on my reticence to employ narration to normalise unstable, possibly unnarratable, elements of patient experience. I ask what purpose this stabilisation and normalisation serves: if words offer protection, I wonder for whom. I think about my experience in hospital, where I did my upmost to protect everyone I loved from my pain – both physical and emotional. I can only surmise that this is something we do for those we love. Being brave, or performing bravery, for ourselves, for others, makes some difference. Indeed, the medical sociologist Nina Hallowell, who has undertaken

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work. The inclusion of *ANAMNESIS II* illustrates a range of material that I work with in my practice as well as drawing attention to the difficult decisions made in the classification of material – as art, reflection, and / or academic writing.

considerable research into women's experiences of genetic conditions, suggests that fundamental to women's decision-making around genetic testing was the placement of the needs of others before their own.[122]

'Where are the stories of failure?'.[123] McKechnie cites Jackie Stacey who writes that stories not fulfilling heroic cancer narratives are left untold, silenced.[124] Drawing attention to a lack of stories that do not follow triumphant, heroic trajectories, McKechnie writes that medical humanities scholars have begun to acknowledge that 'not all stories of illness are helpful – or healthy entities – in the world'.[125] Philosopher Crispin Sartwell writes of the moments in which narratives fail: both the shattering moments and those of indifference.[126] I am reminded of the poem *Hay solo dos paises* by the writer Enrique Lihn.[127] Lihn's final book, *Diario de Muerte* was written in the six weeks preceding his death from cancer. In contrast to transformative narratives, it is flat and bleak, and yet there is consolation, or at least dignity.

The sociologist Anne Kerr writes that an overarching focus on the transformative effects of new genetic technologies on patients detracts attention from 'the social circumstances in which they were developed and the extent to which they reinforce old social arrangements, rather than introduce new ones'.[128] This, she writes, is especially true in pre-implantation genetic diagnosis, which many claim reflects negative views of disabilities.[129] Citing the sociologist Carole Smith, Kerr writes that 'moral thinking has,

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[122] Nina Hallowell, 'Doing the right thing: genetic risk and responsibility', *Sociology of Health and Illness,* 21, 5, 1999, 597–621. Cited in Anne Kerr, *Genetics and Society: A Sociology of Disease*, London: Routledge, 2004, p. 94.

[123] Lisa Diedrich, *Treatments: Language, Politics, and the Culture of Illness,* Minneapolis, MN: University of Minnesota Press, 2007, p. 54. Cited in McKechnie, 'Anxieties of communication', p. 122.

[124] Jackie Stacey, *Teratologies: A Cultural Study of Cancer,* London: Routledge, 1997. Cited in McKechnie, 'Anxieties of communication', p. 122.

[125] McKechnie, 'Anxieties of Communication', p. 4.

[126] Crispin Sartwell, *End of Story: Toward an Annihilation of Language and History*, Albany, NY: University of New York Press, 2000, p. 65. Cited in Woods, 'The Limits of Narrative', p. 76.

[127] Enrique Lihn, *Hay solo dos paises* in *Diario de Muerte,* edited by Pedro Lastra, and Adriana Valdés, Santiago: Editorial Universitaria, 1989, p. 27.

[128] Anne Kerr, *Genetics and Society: A Sociology of Disease*, London: Routledge, 2004, p. 5.

[129] Kerr, *Genetics and Society,* p. 5.

in many ways, been high-jacked by 'rights talk', which reduces everything to a question of peoples' rights and duties and stifles any open and radical discussion of morality'.[130]

Whether the 'quest' narrative is a useful term given its heroic connotations and insistence on individual autonomy – do we carry both of Sontag's passports? – remains to be seen. Perhaps we need a new term to capture the fragmented nature of selfhood in going through illness, or *in being ill,* one that captures the self not as autonomous but as dispersed and in constant process of negotiation with the lived experience of *being ill*. This would also better account for the small stories that shape experience of being ill.

Patient Narratives as Healing

The need for a patient to recount her/his experience is now encouraged as a method of making meaning to enable healing, and various mechanisms – both state-funded and those of entrepreneurial projects – exist to enable the patient to do so. Collections of patient stories, often no more than three minutes duration, are readily available online to any researcher and medic in training as well as the layperson seeking to further an understanding of illness. The personal stories section on the *No Stomach for Cancer* website reads: 'KNOWLEDGE GIVES YOU POWER … SHARING GIVES YOU STRENGTH'.[131]

The restrictive nature of what Frank writes is a 'commonly shared stock of narrative resources that are available to represent what become people's experiences' [132] potentially limits the choices that can be made in narrative construction, compromising the patients' agency and ability to tell their story, potentially negating any healing that narration might beget the patient.

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[130] Carole Smith, 'The sequestration of experience: rights talk and moral thinking in "late modernity"', *Sociology,* 36, 1, 2002, 43–66. Cited in Kerr, *Genetics and Society,* p. 5.

[131] No Stomach For Cancer Inc., *No Stomach For Cancer,* 2015 <http://www.nostomachforcancer.org/our-community/personal-stories> [accessed 28 June 2017].

[132] Frank, 'Practicing Dialogical Narrative Analysis', p. 40.

Patient Narratives as Data

As a source of enquiry across disciplines, patient narratives are thought to challenge dominant medical narratives, not only reclaiming the patients' voice from the biomedical narratives imposed from modern medicine but also leading to further understanding of illness.[133]

The social psychologist Elliot Mishler distinguishes two voices: the 'voice of the life world' – which he claims is often suppressed in medical interviews – and the 'voice of medicine'.[134] The social psychologist Lars-Christer Hydén writes that an insider perspective on illness – Mishler's 'voice of the life world' – has become of great interest to researchers in the social sciences and humanities, more so than illness as understood from the viewpoint of medical institutions.[135] The careers section of the NHS website relating to 'Doctors' indicates the value the NHS currently places on doctors' abilities to access 'the patient's point of view':

> Medicine is about helping people – treating illness, providing advice and reassurance, and seeing the effects of both ill health and good health from the patient's point of view. You have to examine the symptoms presented by a patient, and consider a range of possible diagnoses […].[136]

Using personal narrative as a form of enquiry is thought to elucidate how people make meaning from their experiences through narrative, attending to the way their creators select and relay events in a particular order through emplotment.[137] The restrictive nature of what Frank writes is a 'commonly shared stock of narrative resources that are

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[133] Johanna Shapiro, 'Illness Narratives: Reliability, Authenticity and the Empathic Witness,' *Medical Humanities,* 37, 2011, 68–72, p. 68.

[134] Elliot Mishler, *The Discourse of Medicine: Dialectics of Medical Interviews,* Norwood, NJ: Ablex Publishing Company, 1984. Cited in Lars-Christer Hyden, 'Medicine and Narrative', in *Routledge Encyclopaedia of Narrative Theory,* edited by David Herman, Manfred Jahn, and Marie-Laure Ryan, Abingdon: Routledge, 2005, p. 408.

[135] Ibid.

[136] NHS, *Careers in Medicine* <http://www.nhscareers.nhs.uk/explore-by-career/doctors/> [accessed 28 June 2107].

[137] Ian Parker, *Qualitative Psychology: Introducing Radical Research,* Maidenhead: Open University Press, 2005, p. 73.

available to represent what become people's experiences'[138] potentially negates any insights that might further understanding of illness. Indeed Frank, in considering people's capacity for change, writes that the 'stability of narrative resources – in particular the finite number of character types, plot lines, and genres – allows research reports to draw conclusions and come to an end. This stability of people's resources should not be confused with the finalisation of storytellers themselves.'[139] Through attending workshops aimed at collecting such patient stories, I position myself – as an instrument of my research – in situations that have allowed me to interrogate and experience this supposition further.

In June 2014, I participated in a two-day workshop with Patient Voices. The work accomplished by Patient Voices has had a positive impact on healthcare, but does not adequately accommodate the complex relation between genetic diagnosis and patient narrative. The process of creating a digital story with them was problematic; I found the structure that they adopted too constraining (a 'good story' must include seven elements: point of view, dramatic question, emotional content, opposition, acceptance and transformation, economy of words and images, and attention to pace).

Perhaps sensing the danger of semantic failure, Patient Voices invites patients to include photographic images in their digital stories, arguably exemplifying what bioethicist and art theorist Ulhas Macneil criticises as a 'benign and passive' use of the image, when he calls for work that:

> defies easy understanding and resists being pressed into the service of medicine and other health professions for educational purposes by opening up topics for exploration and discussion without providing unitary explanatory frameworks.[140]

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[138] Frank, 'Trickster narrates the balance of health', in *Communicating for Social Impact,* p. 21–31. Cited in Frank, 'Practicing Dialogical Narrative Analysis', p. 40.

[139] Frank, 'Practicing Dialogical Narrative Analysis', p. 37.

[140] Paul Ulhas Macneill, 'The Arts and Medicine: A Challenging Relationship', *Medical Humanities,* 37, 2011, 85–90, p. 85.

I showed my draft narrative to the workshop leader. After scanning my writing, she questioned my introduction of a new character at the end of my story – I should not do this. 'But that is what happened' I retorted. She (kindly) took the computer on which I was writing and re-wrote my ending. Far from healing, I found the formulaic structures imposed upon me difficult, if not damaging; under these conditions, I was unable to tell my story.[141] Jurecic raises the idea of patient narratives as imperfect but necessary fictions: perhaps narratives of transformation are better viewed as fictions, offering the teller a second chance to rewrite and make sense of patient experiences.[142]

A critique and dialogue focused on the formation of and potential value in these stories may lead to interesting discussion regarding their use in medical practices, but I am not convinced that this is how they are used. I am wary of their use for medical training purposes because despite their presentation as the patients' own voices, what the patient says is often heavily shaped by the narrative resources available as well as the interviewer's questions and agenda.

The Imposition of Narrative

Contrary to Frank's optimistic position – that patients now have the (narrative) resources to reclaim control over the telling of illness – the following narrative vignettes, which centre on two conversations between a *locum* doctor and me, provide evidence for the continuing imposition of narrative and consequent narrative surrender Frank describes.

The first conversation took place in 2014 and involved an appointment to have my three- monthly vitamin B12 injection, an appointment that I made two days early (the practice is often full, it is difficult to make an appointment on the exact day, I was lethargic and knew that my vitamin levels were low). The nurse's computer alerted her that I was early and, despite having been given the appointment; she refused to give

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[141] The final digital story is found on DVD in Appendix One.

[142] Jurecic, *Illness as Narrative*, p. 42.

permission to inject me. I asked to see the doctor, whose permission she required. The doctor, who was not seeing patients in the surgery but was on telephone duty, made me wait for over an hour before she called me into her office. She was abrupt and did not invite me to sit down. I pretended not to notice her attitude and explained my situation: if I took the next available appointment, my injection would be overdue and I was feeling fatigued. When I realised this approach was not working, I said that I was going away to my parents so I had to have the injection that day. She relayed an adapted version of my story to me, awaiting my confirmation. I confirmed to get the injection. She typed this new account (her account) into the computer. She spoke to me as if I were a poorly behaved child, taking one last opportunity before I left to chastise me. I was furious – but I got the injection.

A second encounter with the same doctor, this time a telephone conversation, occurred following a night of abdominal pain. I was familiar with the pain – adhesions and resulting bowel obstruction. I did not have any painkillers at home and, unable to call for help, I had to endure the pain until it subsided. The following day, I telephoned the surgery to request some pain relief should it occur again (it frequently does reoccur and I feared more episodes). I am well versed as to the procedure to follow during such episodes, having been advised by my consultant. I relayed the experience to the doctor. She insisted that this was not the pain I experienced; according to her, it was different from the pain I had previously experienced (abdominal pain) and I was refused any pain relief.

These vignettes reveal an obstacle in the process of communicating (my) patient experience and the potential shortcomings of current medical narrative practices.[143] McKechnie's article, 'Anxieties of communication: the limits of narrative in the medical humanities', focuses on the role of the narratee of patient narratives. McKechnie idealises this role and its position in the medical encounter, drawing on the work of the medical anthropologist Arthur Kleinman to claim that 'ordering experience means creating a narrative that can help the health professional to understand the

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[143] This does not exclude that she could also be a very bad doctor.

patient's situation and enable the patient to feel heard and cared for'.[144] She writes that the doctor's attempt to help order the patient's experience – where the patient is unable to tell her/his story as s/he would like – can be restrictive and damaging. My own experiences relayed above indicate that this may be the case even when the patient is able to tell her/his story. Returning to Cancer Research's logo 'together we will beat cancer', 'together' is the operative word. Power relations would not exist without the binding together of these two groups – of patients and doctors – with narrative as the subtle or 'diffuse' mode through which power is exerted.

In Summary

Throughout the history of patient narrative new voices have repeatedly presented challenges to dominant contemporary institutional and cultural thinking, only to subsequently become incorporated into such thinking as it evolves. While such incorporation certainly offers hope that the resources provided by patient narratives may be used with increasing effectiveness, the tendency of these voices to be bent to the needs of the institution or culture has often meant that something is lost.

Genetic medicine presents new challenges to the narration of patient experience. These challenges – which coalesce around risk, causality and indeterminacy, agency, and patient identity – are considered in the next section, forming a rationale for expanding the narrative resources currently dominating the field of patient narrative.

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[144] McKechnie, 'Anxieties of Communication', p. 120.

Patient Narrative Part III: Towards a Genetic Patient Narrative

Genetic Risk — Biographical Illness Narratives and Genes as Causal Factors — Indeterminacy — Agency — Genetic Patient Identity

Genetic Risk

'[…] Emma O'Connor is at high risk of developing gastric cancer.'[145]

When diagnosed with the CDH1 genetic mutation, I had to make decisions about my health based on risk and statistics. There were no right answers and no recommended routes. Despite diagnosis, I was not offered a clear narrative, trajectory, or prognosis – only risk. Distinct from a diagnosis of cancer, I was diagnosed with the risk of stomach cancer. In narrative terms, I was given the risk of an event, not the event itself.

Drawing on the sociologist Ulrich Beck's *Risk Society,*[146] Jurecic describes the twenty-first century as a time when the risk society has intersected with the genomic age.[147] She goes some way to examine what a genetic patient narrative might look like, turning first to risk narratives, which she defines as 'autobiographical and literary explanations of the meaning of risk'.[148]

Jurecic examines *The Median Isn't The Message*, a personal story about the statistics of prognosis with a rare form of stomach cancer written by evolutionary biologist Stephen Jay Gould.[149] Gould's goal, writes Jurecic, was to use his experience of diagnosis to educate patients about statistics and to change their attitudes. However, Jurecic observes that the piece has since been co-opted by cancer support websites for a different purpose

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[145] Report Summary, West Midlands Regional Genetics Laboratory.

[146] Ulrich Beck, *The Risk Society: Towards a New Modernity,* translated by Richard Miller, London: Sage, 1992 [*Risikogesellschaft: Auf dem Weg in eine andere Moderne,* Frankfurt am Main: Surbkamp Verlag, 1986].

[147] Jurecic, *Illness as Narrative,* p. 26.

[148] Jurecic, *Illness as Narrative*, p.19.

[149] Stephen Jay Gould, 'The Median Isn't The Message', *Discover,* 1985, 40–2.

– to show triumph over adversity (typical of a quest narrative), thus losing its relevance as a narrative of statistics.[150] This re-positioning of Gould's narrative, writes Jurecic, permits readers to avoid the full complexity of living with risk and prognosis.[151]

Having read Jurecic's book, I arrived at Gould's piece *via* the website *Cancer Guide*.[152] Steve Dunn's preface introduces Gould not as a patient but as an eminent scientist, implying that the import of the piece might be attributed to Gould's status, not simply as patient but as a world-renowned patient. Gould as patient is secondary to Dunn's message of hope; Gould's narrative introduced thus is an antidote and a weapon that 'anyone who reads this will be armed with reason and with hope'. This relegates Gould's status as patient, focusing the reader on what use s/he might extract from the narrative, as if it were a self-help text. Framing his remarks around readers' apparent solicited requests, Dunn writes two short paragraphs at the end of Gould's piece which function to bring hope to the reader. The reader's solicitation for news of Gould in combination with Dunn's framing of Gould's narrative reduces the experience and patient narrative of Gould to its utility.

However, Dunn's framing does not alter the essence of Gould's piece, which uses his professional knowledge to examine what it is to be a patient in the midst of statistics. Aware that Gould was an evolutionary professor, I was curious to discover what tools of language he would employ to tell his personal story. There are three Aristotelian principles of rhetoric or persuasion: the calls to *ethos, logos,* and *pathos*. Gould relies on logos, employing scientific language to explore statistics. The most frequent content words in his piece relate to statistics: *median* (13); *right* (12); *variation* (12), and *statistics* (9). The next most common word is *death*. Gould, an academic, was

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[150] I am wary of the insistence on positive thinking, and worse the claims that a positive attitude can cure diseases such as cancer. While the negative impact of stress on health is evident, it has not yet, as far as I am aware, been proven that a positive attitude can cure cancer. To the contrary, *Smile or Die* by Barbara Ehrenreich (Babara Ehrenreich, *Smile or Die: How Positive Thinking Fooled America & The World*, London: Granta Books, 2009), author and political activist, also diagnosed with cancer, suggests that the impact of pressure to be continually positive on sufferers of cancer has negative consequences.

[151] Jurecic, *Illness as Narrative,* p. 24.

[152] Stephen Jay Gould (Prefatory Note by Steve Dunn), 'The Median Isn't the Message', *Cancer Guide: Statistics,* Cancer Guide <http://cancerguide.org/median_not_msg.html> [accessed 28 June 2107].

presumably well versed in writing cohesive texts. Despite repetition being a tool of cohesion, employed particularly when writing for a lay audience to help the reader follow the text, the high frequency words in Gould's text are specific to his area of expertise. This is more apparent when compared with the Bendle's narrative discussed earlier in this chapter.

The epistemological lexis distinguishes Gould's piece from many other patient narratives. Rather than mastering medical discourses, Gould empowers through using language from another field, establishing a status equal to but also different from many doctors or cancer patients.

Gould also relies on ethos, both his and others, connecting his narrative and experience to a discussion of science and knowledge. To a lesser degree, he employs pathos as well: 'I realised with a gulp why my doctor had offered that humane advice […] I sat stunned […] then smiled.'

Later, Gould employs language of warfare. It is perhaps here, through adopting a language commonly associated with cancer, that Gould most strongly identifies as a patient.

Gould ends his narrative with humour: 'Just think, I almost got to repeat Mark Twain's most famous line of all: the reports of my death are greatly exaggerated.'[153] This allows for closure through a means that does not negate that Gould does not know how his illness will end. Yet Jurecic writes that Gould's survival long after his diagnosis presents readers with a happy ending that many use to make generalisations about their own lives, avoiding the complexities of risk.[154] Highlighting the struggle between the demands of closure and the nature of risk in the risk society, Jurecic writes that closure misrepresents the fundamental indeterminacy of life.[155]

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[153] Stephen Jay Gould (Prefatory Note by Steve Dunn), 'The Median Isn't the Message', *Cancer Guide,* Cancer Guide <http://cancerguide.org/median_not_msg.html> [accessed 28 June 2107].

[154] Jurecic, *Illness as Narrative*, p. 39.

[155] Jurecic, *Illness as Narrative,* p. 38.

Biographical Illness Narratives and Genes as Causal Factors

Kerr writes that biographical illness narratives tend to privilege genes as causal factors in patients' illnesses and experiences thereof.[156] Exemplifying Kerr's observation is Joy's story on the *Telling Stories* website – a site developed for health professionals to disseminate knowledge and increase understanding of genetics.[157] Joy has the BRACA 2 gene for breast cancer, which from my point of view is the closest resemblance to the CDH1 mutation. Joy's genes are framed in such a way that they are causative at the expense of any other relations that might have been chosen by Joy to articulate her experience of her genetic illness.

The story is entitled 'Joy's story, the positive impact of cancer', immediately framing the text as one that will end positively, suggesting the quest narrative type.[158] Kerr writes that the concept of transformation is often found in genetic discourses, which take the aim of perfect health as the goal of modern genetics.[159] Sociological research, writes Kerr, foregrounds the transformative properties of genetic technologies on patients, highlighting the desirability of genetic diagnoses and treatments to 'predict and cure genetic disorders'.[160]

I discovered that Joy's story is actually a series of responses – narrative vignettes – to questions from an interviewer. Framed as data, each of Joy's responses are mapped against a competency framework for health practitioners and a separate document, relating competencies explicitly to Joy's story, provides further information and activities to support learning and teaching. *Telling Stories* website cites evidence 'that stories are useful in education as they can help promote understanding of often quite complex situations, linking theory to practice in a way that is memorable. [...] In doing

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[156] Kerr, *Genetics and Society*, 2004, p. 9.

[157] NHS National Genetics and Genomics Education Centre, *Joy's Story – The Positive Impact of Cancer,* 2007-2014 <http://www.tellingstories.nhs.uk/index.php/background> [accessed 28 June 2107].

[158] Joy's story exemplifies Frank's restitution narrative; the medical support she has received is viewed as restorative.

[159] Kerr, *Genetics and Society,* p. 2.

[160] Kerr, *Genetics and Society,* p. 6.

so, we hope the stories will provide educators with a useful teaching resource, and will help learners to understand 'real-life genetics.'[161]

The first point Joy is asked to discuss pertains to the genetic condition in her family history; she is then asked to place herself within this lineage. Joy is asked how she got her results and how this made her feel. The interviewer asks Joy specifically about the actions of her geneticist – whether they took a family history or drew a family tree. Joy is asked whether she underwent treatment before being probed again about when she discovered the genetic link in her family and to which health services she was referred. She is then asked about genetic testing, decision-making, and any counselling she might have attended. Each time, the interviewer asks Joy to describe the actions of and explanations given by the health professionals she encounters. Joys' story continues in this manner – she responds to specific evaluative questions about her dealings with the health service.

Kerr writes that the privileging of genes as causal factors leads to the neglect of 'the myriad relations that shape how people come to articulate their experience of disease'.[162] Jurecic writes about the death of genetic determinism and the arrival of a new understanding of genes as 'complex, interactive and contested entities'.[163]

Referring to patients of genetic medicine who invariably face prognosis before they are sick, Jurecic writes that 'popular narratives of genetic determinism oversimplify and overwrite the complexity of individual experience'.[164] She cites critic Kathleen Woodward's warning against seeing genomes as a script without understanding that the numbers refer to general probabilities that must be interpreted, not to facts.[165] In Jurecic's analysis of *Swimming in a Sea of Death,* David Rieff's memoir about his

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[161] NHS National Genetics and Genomics Education Centre, *Telling stories,* 2007-2014 <http://www.tellingstories.nhs.uk/index.php/background> [accessed 28 June 2107].

[162] Kerr, *Genetics and Society,* p. 9.

[163] Jurecic, *Illness as Narrative,* p. 7.

[164] Jurecic, *Illness as Narrative,* p. 28.

[165] Woodward, Kathleen, 'Statistical Panic', *Differences: A Journal of Feminist Cultural Studies*, 11, 1999, 177–203. Cited in Jurecic, *Illness as Narrative,* p. 28.

mother Susan Sontag,[166] she writes that the central challenge faced by Rieff is the impossibility of fully accounting for survival by statistics. Jurecic concludes that personal narratives, rather than probabilities, might provide the structure for making meaning in the face of one's own insignificance.[167]

Biographical illness narratives that posit genetic mutations as causes that create effects, neglect to account for chance: genetic mutations (as far as is known) arise by chance; furthermore, some hereditary diseases, even when no preventative treatment is undertaken, do not surface. In a discussion of postmodern narratives of chance and Darwin's theory of natural selection, H. Porter Abbott writes that despite being an element of narrative, chance when everywhere 'transcends the limit of tolerable narrative' and when acknowledged as such, the 'resistant and intolerable story that remains is strangely post-modern'.[168] Jurecic writes that failure to contain the uncontainable is not failure but indicative of the relation of narrative to risk.[169]

Indeterminacy

Drawing on narrative theorist David Herman's exploration of the distortions created when events are organised with narrative,[170] Jurecic writes of the temptation to infer causation when events follow one another even when a valid causal relation may not be identified.[171] Indeterminacy presents a challenge to narrative, to the narrator and the narratee, who too may search for causative events. Narrating indeterminacy is a particular challenge for patients with a genetic diagnosis because there is no certainty if

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[166] David Rieff, *Swimming in a Sea Of Death: A Son's Memoir,* New York, NY: Simon and Schuster, 2008.

[167] Jurecic, *Illness as Narrative,* p.25.

[168] H. Porter Abbott, 'Unnarratable Knowledge: The Difficulty of Understanding Evolution by Natural Selection', in *Narrative Theory and the Cognitive Sciences,* edited by David Herman, Stanford, CA: Centre for the Study of Language and Information (CSLI), 2003, 143–62, p. 148. Cited in Jurecic, *Illness as Narrative*, p. 30.

[169] Jurecic, *Illness as Narrative,* p.33.

[170] David Herman, 'Stories as a Tool for Thinking', in *Narrative Theory and the Cognitive Sciences,* edited by David Herman, Stanford, CA: Centre for the Study of Language and Communication, 2003, 163–92, p. 170. Cited in Jurecic, *Illness as Narrative,* p. 24.

[171] Ibid.

the genetic mutation will affect their health. Indeed, the challenge to narration comes not from the event, but rather its risk.

Agency

The agency afforded any narrator may be understood in terms of the choices s/he makes in narrative construction. However, Kerr, referring to contemporary preoccupations with choice, cites a body of convincing research demonstrating that choices are not autonomous.[172] She contrasts this with the rhetoric surrounding genetics concerning informed individual choice, with clinical services often seen as having the potential to empower patients in this decision making process.[173] My experience of genetic medicine has also revealed an emphasis on my individual choice despite my feelings to the contrary.

Genetic Patient Identity

The complexities and uncertainties involved in undergoing genetic testing and preventative surgery raise particular questions regarding patient identity. On receiving a genetic diagnosis, do we become sick? If so, post-surgery, are we then 'well'? After undergoing preventative surgery, patients who look well and whose bodies do not host disease may feel that they must live up to social expectations of being well, despite experiences to the contrary.

Kerr, challenging dominant conceptions of what it is to be a patient, writes that psychosocial approaches to genetic conditions tend to pathologise people's experiences, rooting them in 'an underlying biological deficiency', reducing people to patients – ignoring 'the other identities they might assume in their daily lives'.[174] However, Kerr goes on to review other work that reveals that the 'identity of 'patient' is not

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[172] Kerr, *Genetics and Society*, p. 6.

[173] Ibid.

[174] Kerr, *Genetics and Society*, p. 11.

hegemonic',[175] before concluding that more thought should be given as to how people come to be categorised as patients, if it is appropriate to analyse their experiences as such.[176] It may be that the reliance on and seeking of a homogenous patient identity has arisen from a need for efficiency in healthcare research – just as Abbott writes that types are used in narrative for efficiency. [177]

Two interactions between the public and me further illuminate the rationale for exploring the term 'patient' as applied in medical genetics. The first occurred when I presented my work to medical students at Cambridge University. During the question and answer session, I was asked if I was still receiving treatment, to which I replied no. This brief interaction – between a medical student and me – led me to believe that he no longer thought of me as a patient; after all, at that time I had been discharged from my surgeon's supervision. Reflecting later, I believed that he did not think that my experience of illness post-gastrectomy identified me as a patient, a conclusion I would at times contest. The second situation occurred at the Design for Health Conference at Sheffield Hallam University in 2015. In the central reception, an area was an area made available for conference attendees to write comments, I was intrigued to see someone had written 'where are all the service users?' Unable to locate the person who made this comment for discussion, I was shocked that an attendee of a conference devoted to health would display what I consider to be a narrow conception of a 'service user' which I, perhaps misguidedly, equate as a 'patient'. I imagined the commentator to have been referring to a troop of hospital inmates dressed in backless gown, conspicuous by their absence. Of course many of us are patients at times.

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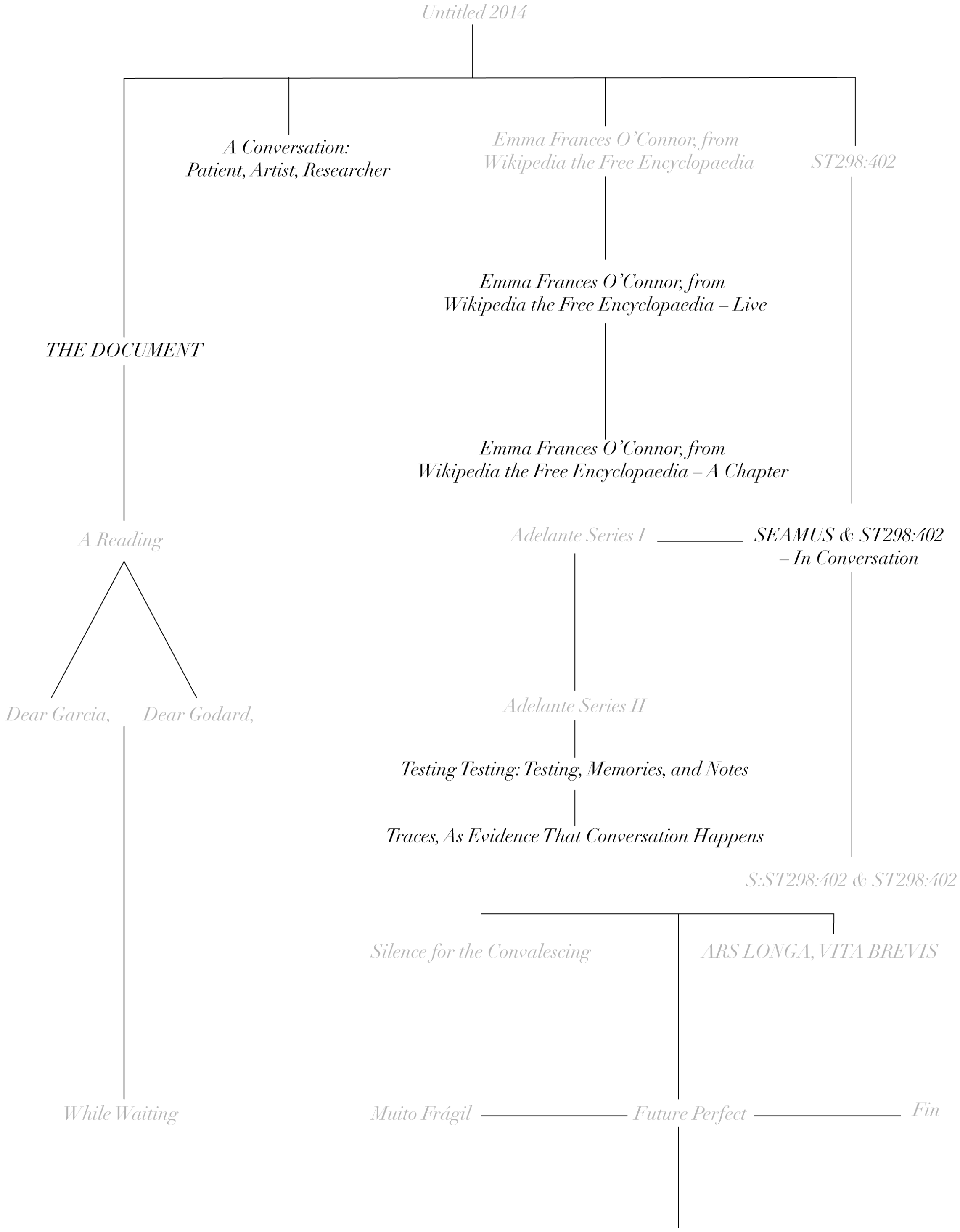
[175] Ibid.

[176] Kerr, *Genetics and Society*, p. 7.

[177] Abbott, *The Cambridge Introduction to Narrative*, p. 139.

PÉ DE GRUE —— PEDIGREE II



PÈ DE GRUE ———— PEDIGREE II

A Conversation: Patient, Artist, Researcher — THE DOCUMENT —
Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia – Live —
Seamus &ST298:402 – In Conversation — Testing, Testing: Testing, Memories, and
Notes — Traces, as Evidence That Conversation Happens

A Conversation: Patient, Artist, Researcher

I was thinking about the multiple positions I occupy in my work and *A Conversation: Patient, Artist, Researcher* explores my occupation of multiple positions. I was reading about triangulation and *A Conversation: Patient, Artist, Researcher* is arranged spatially to explore the gathering of information from multiple perspectives. The diverse methods I employ produce a multi-perspective, textured approach that is beneficial for the full analysis of patient experience and subjective narratives.

THE DOCUMENT

THE DOCUMENT is a 24-page softback publication, in a numbered edition of 25. It was produced as part of *The Editions II*, MA BIBLIOTHÈQUE, edited and published by Sharon Kivland in the series: THE GOOD READERS. *THE DOCUMENT* contains a script for a scene in a film – seven characters discuss how to read a document that came into their possession thirteen days ago. This document is a patient narrative. In the end, much of the script revolves around two characters discussing what a perfect patient narrative might be. I was reading many patient narratives; thinking about what might constitute a good narrator and a good narratee of a patient narrative.

Testing, Testing: Testing, Memories, and Notes

Testing, Testing: Testing, Memories, and Notes is a text work with accompanying documentary images of *Adelante – Series II.*[178] *Testing, Testing: Testing, Memories, and Notes* is a largely unedited experimental work, which pieces together fragments of fieldworks notes and diary entries. The work recalls the time before and after my meeting with a leading pathologist in Porto. I write about the lines on the hospital floor, the filming of which becomes the video element of my work. *Adelante – Series II. Testing, Testing: Testing, Memories, and Notes* is simultaneously a work and a reflection on a work.

Traces, as Evidence That Conversation Happens

In making *Traces, as Evidence That Conversation Happens* I was thinking about how I might describe the process of my making; specifically how notes and diary entries are or can become work. I also reflect on presenting work and inviting discussion in a crit format. In assembling this piece, I tried to retain the liveliness of the writing in my notebooks.

Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia – LIVE

In this iteration, *Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia – LIVE*, the text element of the work became a live Wikipedia page at the beginning of the performance at In Dialogue 2014. A recording of the work can be viewed here: <https://www.youtube.com/watch?v=9IVJoSNqv8U> [179] I had been reading about autoethnography and the work was intended as a direct challenge to Wikipedia's stance on autobiography and as an invitation for dialogue on the value of one person's story.

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178 *Testing, Testing: Testing, Memories, and Notes* and *Traces, as Evidence That Conversation Happens* are part of *Testing Testing* – a project that explores the process of artistic production as research methodology, initiated and produced by practice-based Ph.D. researchers in fine art at Sheffield Hallam University. The project takes the form of an exhibition at SIA Gallery, a symposium event, and two publications *Testing, Testing: Prologue (vol. 1 and vol. 2)* <http://testingtesting.org.uk/index.html> [accessed 28 June 2107].

179 In Dialogue is an international symposium, held at Nottingham Contemporary, about dialogue in artists' and researchers' practices <http://www.nottinghamcontemporary.org/event/dialogue-2014> In Dialogue 2014 is co-curated by Rebecca Beinart, Heather Connelly, and Rhiannon Jones. Dr Gillian Whiteley chaired the event.

Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia – A Chapter

I was reading Stone's *Running Man* and thinking about the place of refection and interpretation in autoethnographic works at the same times as writing a version of *Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia* for a publication. In this iteration, *Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia* frames my personal narrative with a written traditionally academic text, which adds context and interpretation. The requirement that I explicitly frame *Emma Frances O'Connor* in this way corroborates the assertion of Ellis, Adams, and Bochner, when they write that autoethnographers must, in addition to telling their experiences, analyse them – a requisite which they assign to the publishing requirements of social science.[180] In other autoethnographic works, I do not use the conventions of form to differentiate spatially between the two types of writing – here movement between my personal narrative and reflection is fluid, with both occurring in the body text.

SEAMUS & ST298:402 – In Conversation

SEAMUS & ST298:402 – In Conversation extends from *ST298:402*. *ST298:402* is shown on a small monitor next to *SEAMUS* a 30-minute video work in which my grandfather tells the story of his life. Reading about autobiography, I was thinking about my experience of genetics and how it relates to both past and future time. I revisited the video of my grandfather and thought of it as my first patient narrative.

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[180] Ellis, Adams, and Bochner, 'Autoethnography: An Overview", p. 3.

Linhas de Vapor

Perceiving the World – Autoethnography (and its ethnographic relation … its autobiographic relation … its relation to the past … autoethnography and art … doing autoethnography) – Diary Writing – Making Reflection – Personal Narrative – My Quest Narrative – Befriending – Ethical Considerations — Autoethnographic Practices and An Ethics of Self-Care — Image, Capture, Edit – Making and Presenting Work – Exploring the Work of Others

Perceiving the World

> *Before passing into general use, however, discoveries of methods and means have to come about as the only natural way for an artist, using [her or] his own language to communicate as fully as possible [her or] his own perception of the world*.[181]

The philosopher Donald Alan Schön writes: 'a practitioner's stance toward inquiry is [her or] his attitude toward the reality with which [she or] he deals'.[182] Parker writes that what can be found and the sense that researchers make of their findings is contingent on the researcher's position (from which they are trying to make sense) and what the researcher thinks s/he will find.[183]

Jean-Luc Godard's 1982 film *Passion* explores the conception of art as the 'repository of an essential truth' and 'as a vehicle for the revelation of something fundamental about being human'.[184] Filmmaker Jerzy (Jerzy Radziwiłowicz), one of three central characters in *Passion*, is directing a film, also called *Passion,* composed of *tableaux*

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[181] Andrey Tarkovsky, *Sculpting in Time: Reflections on the Cinema,* translated by Kitty Hunter-Blair, Austin, TX: University of Texas Press, 1986, p. 102.

[182] Donald Alan Schön, The Reflective Practitioner: How professionals think in action, London: Temple Smith, 1983, p. 163. Cited in Carole Gray and Julian Malins, Visualizing Research: A Guide to the Research Process in Art and Design, Aldershot: Ashgate, 2004, p. 163.

[183] Parker, *Qualitative Psychology,* 2005, p. 27.

[184] Maria F. Marquez, 'Art and Women as Thresholds of the Sublime: The Gendered Limits of "the method of BETWEEN" in Godard's *Passion*', *Australian Journal of French Studies,* 49, 1, 2012, 18–30, p. 22.

vivants. Jerzy searches for something in the *tableaux vivants*; a search which rests on – and is ultimately restricted by – his belief that 'images are surfaces that conceal essential Truth, and the reconstruction and filming of great works of European art enable him to inspect and penetrate these surfaces'.[185] Jerzy believes this essential Truth will be revealed with the correct lighting but as the conditions for this revelation never materialise, he is left with a failed project.[186] The film theorist Maria F. Marquez writes of Jerzy's 'inability to witness the revelation that he expects from the construction of the tableaux'.[187] Marquez connects Jerzy's search with Martin Heidegger's writing: 'The art work opens up in its own way the Being of Things. This opening up, i.e., this deconcealing, i.e., the truth of beings, happens in the work.'[188] In contrast, Jerzy equates this Truth with a mystery that he identifies as the sacred, and towards which he employs his camera – in search of knowledge as opposed to its perception or creation.[189]

Jerzy's failure is a consequence of his clinging unflinchingly to specific beliefs about art – surfaces that conceal irreducible mystery accessible only through aesthetic experience, informing his approach to his film *Passion*.[190] Unlike Jerzy, I have an overriding sense of not wanting to foreclose anything. Rather than an initial affirmation of my ontological, epistemological, and methodological positions, I adopt an open attitude towards what is knowable in my discipline and what can be researched through employing multiple methods.

Artists and researchers Carole Gray and Julian Malins question the position a researcher should adopt in her/his research.[191] They write that a pluralist approach, with a 'multi-method technique tailored to the individual project', is a common characteristic of

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[185] Marquez, 'Art and Women as Thresholds of the Sublime', p. 23.

[186] Ibid.

[187] Ibid.

[188] Martin Heidegger, *Poetry, Language and Thought*, translated by Albert Hofstadter, New York, NY: Harper 2001, p. 38. Cited in Marquez, 'Art and Women as Thresholds of the Sublime', p. 23.

[189] Ibid.

[190] Marquez, 'Art and Women as Thresholds of the Sublime', p. 29.

[191] Carole Gray and Julian Malins, *Visualising Research: A Guide to the Research Process in Art and Design,* Aldershot: Ashgate, 2004, p. 19.

methodology in art.[192] Examining an issue from different perspectives helps in understanding the complexity of the matter under investigation.[193] The more information gleaned from varying methods, the more one is able to test ideas. Involving the spectrum of human senses and independent sensory instruments offers a 'comprehensive and "rich" perspective on the research issue being explored'

Autoethnography

Despite being a variable, adaptable term, most researchers acknowledge autoethnography as an approach that aims to 'describe and systematically analyse (graphy) personal experience (auto) in order to understand cultural experience (ethno)'.[194]

The emergence of autoethnography is often contextualised with a genealogical explanation to 'elucidate the material and intellectual conditions that made possible the formulation of particular concepts, objects, and discourses'.[195] In the wake of postmodernism, autoethnography developed alongside a growing scepticism towards claims made in social science for the existence of objective truths and universal master narratives,[196] new understandings of the relations between texts, authors, and audiences proposed in the work of Roland Barthes, Jacques Derrida, and Janice Radway,[197] and a disquiet concerning the exploitative colonial research practices of anthropology and the

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[192] Gray and Malins, *Visualising Research,* p. 21.

[193] Gray and Malins, *Visualising Research,* p. 31.

[194] Carolyn Ellis, *The Ethnographic I: A Methodological Novel About Autoethnography*, Walnut Creek, CA: AltaMira Press, 2004 and Stacy Holman Jones, 'Autoethnography: Making the Personal Political', in *Handbook of Qualitative Research,* edited by Norman K. Denzin and Yvonna S. Lincoln, Thousand Oaks, CA: Sage, 2005, pp. 763–91. Cited in Carolyn Ellis, Tony E. Adams, Arthur P. Bochner, 'Autoethnography: An Overview', *Forum: Qualitative Sozialforschung/Forum: Social Research,* 12, 1, 2011 <http://nbn-resolving.de/urn:nbn:de:0114-fqs1101108> p. 1.

[195] This definition by Joelle M. Abi-Rached and Nikolas Rose is in a paper on the emergence of neuroscience: Joelle M. Abi-Rached and Nikolas Rose suggest a genealogical explanation to Joelle M. Abi-Rached, Nikolas Rose, 'The Birth of the Molecular Gaze', *History of the Human Sciences,* 23, 1, 2010, p. 16.

[196] Ellis, Adams, and Bochner, 'Autoethnography: An Overview', p. 1.

[197] Roland Barthes, *Image Music Text,* translated by Stephen Heath, New York, NY: Hill and Wang, 1977; Jacques Derrida, *Writing and Difference*, translated by Alan Bass, Chicago, IL: University of Chicago Press, 1978 [*L'écriture et la différence,* Paris: Éditions du Seuill, 1967]; Janice A. Radway, *Reading the Romance: Women, Patriarchy, and Popular Literature,* Chapel Hill, NC, University of North Carolina Press, 1984. Cited in Ellis, Adams, and Bochner, 'Autoethnography: An Overview', p. 1.

imposition of ethnocentric ideas.[198] The 'biographical turn' in the social sciences – with its focus on individual, personal, subjective, social, and cultural meaning – is also pertinent.[199] Deriving from a range of disciplines as a move to more empathetic representational forms that take into account lived experience, autoethnography appeals to researchers interested in grounding their work in personal experience, offering readers knowledge that is 'self-consciously value-centred'.[200]

Autoethnography and its Ethnographic Relation

Although informed by a range of disciplines, autoethnography combines tenets of autobiography – the selective and retroactive writing about significant past experiences – and ethnography.[201] Ethnography is a mixed-method approach, its output frequently narrative. To present a picture of what people think about their experience, ethnographers often live in natural settings for long periods of observation. As a totalising and immersive form of research, ethnography takes time and with this time, the researcher gets to know the subject of her/his research in detail. Like ethnography, autoethnography is an inductive approach; data, rather than theory, is the researcher's starting point; data is used to build theory. Ethnography is iterative – data on a theme is presented and ethnographers look to theory to explore the data before moving back to the data, and then to the theory. Good ethnography is supposed to include (and clearly demarcate) insider and outsider perspectives, uncovering insider perspectives of reality and accounting for researchers' views of reality.

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[198] Dwight Conquergood, 'Rethinking Ethnography: Towards a Critical Cultural Politics', *Communication Monographs,* 58, 1991, 179–194; Carolyn Ellis, 'Telling Secrets, Revealing Lives: Relational Ethics in Research with Intimate Others', *Qualitative Inquiry,* 13, 1, 2007, 3–29; Agnes Riedman, *Science that Colonizes: A Critique of Fertility Studies in Africa,* Philadelphia PA, Temple University Press, 1993. Cited in Ellis, Adams, and Bochner, 'Autoethnography: An Overview', p. 1.

[199] Prue Chamberlayne, Joanna Bornat, and Tom Wengrafdel (eds), *The Turn to Biographical Methods in Social Science: Comparative Issues and Examples,* London and New York: Routledge, 2000, p. 1.

[200] Arthur P. Bochner, 'Perspectives on Inquiry II', in *Handbook of Interpersonal Communication,* edited by Mark L. Knapp and Gerard R. Miller, Thousand Oaks, CA: Sage, 1994, pp. 21–41, cited in Ellis, Adams, and Bochner, 'Autoethnography: An Overview', p. 2.

[201] Ellis, Adams, and Bochner, 'Autoethnography: An Overview', pp. 1–2.

Autoethnography and its Autobiographic Relation

Given autobiography's long literary history, autobiographers inevitably draw on its modes and models of expression, which, write Barbara Steiner and Jun Yang, 'owe their existence to particular conventions and social contexts'.[202] Writing autobiography can be viewed as a 'cultural technique of self-depiction and self-assurance' – subject to change according to prevailing ideas about the meaning of self.[203] Ellis writes that autoethnographers must use their experience to illustrate cultural experience, making characteristics of a culture familiar for those inside and outside that culture.[204]Autoethnographers should aim to produce 'aesthetic and evocative thick descriptions of personal and interpersonal experience'.[205] In this way, patterns of cultural experience – evidenced by field notes, interviews, and/or artefacts – are discerned and then described, using storytelling, showing and telling, and authorial voice/s.[206]

Brendan Stone's autoethnography *Running Man* explores his experience of anorexia, extreme exercise, and psychosis, drawing together the shaping of the body through starvation and the shaping of identity through narrative management and repression of traumatic memory.[207]

Running Man takes the form of an article; consisting of an abstract, a lengthy introduction, and *Running Man* – a creative writing piece or 'enigmatic articulation'.[208] Ellis, Adams, and Bochner write that autoethnographers must, in addition to telling their experiences, analyse them – a requisite which they assign to the publishing requirements of social science.[209] In his introduction, Stone contextualises, theorises,

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[202] Steiner and Yang, *Autobiography,* p. 11.

[203] Ibid.

[204] Ellis, Adams, and Bochner, 'Autoethnography: An Overview', p. 3.

[205] Ellis, Adams, and Bochner, 'Autoethnography: An Overview'', p. 4.

[206] Ibid.

[207] Brendan Stone, 'Running Man', *Qualitative Research in Sport and Exercise,* 1, 1, 2009, p. 69.

[208] Ibid.

[209] Ellis, Adams, and Bochner, 'Autoethnography: An Overview'', p. 3.

and interprets *Running Man*. He draws on the work of Judith Butler to emphasise the importance of form in communicating experience, establishing the necessity of artistic forms of expression, which lie outside academic and narrative writing, 'to produce findings and insights not readily discoverable *via* more conventional research methods'.[210] Stone reflects on the stuttering tone and style of *Running Man,* interpreting this as indicative of dialogues between 'versions of the self' – 'not simply the self in the twin roles of the one who remembers and narrates and the one who is remembered and narrated, but also the "interanimation" of these subject positions.'[211] Just as the present writing self emerges from, is informed by, and maintains a close relation with its previous manifestations, it also constructs and informs the historical narrated self.[212]

Autoethnography and its Relation to the Past

Autoethnographic practices are understood as retrospective: what was is considered in the present by the author and the reader. Autoethnographies commonly focus on extracts of an individual life, rather than a whole life. The artist Jo Spence uses auto-ethnographic methodologies to chart her life, in particular her struggle with breast cancer, producing photographic works that represent her multiple, fragmented selves. Accounts of illness as biographical disruption imply that a patient narrative focuses on a limited period as opposed to an account of a life. In my case, this would likely include genetic testing, diagnosis, and prophylactic surgery. However, the relevant period is less easy to demarcate – I can look backwards and forwards, as well as laterally, to consider different possibilities. My intention is not to construct an account of my life. Decisions about where to begin and end my narratives are significant.

The retrospective nature of autoethnography seems to exist due to an implicit belief that only those things that have been experienced – lived through – can be known sufficiently to form the basis of a written autoethnographic account. However, I fear

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[210] Stone, *Running Man,* p. 69.

[211] Stone, *Running Man*, p. 70.

[212] Ibid.

that the retroactive nature of autoethnography potentially forecloses possibilities. In genetic diagnosis future time is important – statistics await consideration and decisions must be made about genetic testing, preventative surgery, and family planning. Adam Phillips, in his Empson Lecture 'Against Biography', says that Sigmund Freud believed biographies to be the enemies of the future due to their restrictive truth claims.[213] Using the adjective 'sepulchral', Phillips speaks of biography as entrapment due to its fixity with the past at the expense of the future. With the future at stake, he raises questions about what kinds of biography could enable an original relation to the world, subjects, selves, and futures. Art practice, employed to visualise potentiality, might leave open possibilities and futures.[214] Art, employed in the field of genetic patient narrative, might support the exploration of multiple, potential versions of the future as well as the past.

Autoethnography and Art

The reliance on literary forms in autoethnography is intriguing, as ethnography is a mixed-method approach and, like visual anthropology, encompasses well-established visual methods, as may be seen in the following examples. Ethnographer Michael Taussig writes an entire book – *I Swear I Saw This* – from a single drawing made in his field notes in Colombia.[215] Agnes Varda's documentary film *Les glaneurs et la glaneuse* combines handheld camera shots with a voice-over narrative often in the present continuous tense – 'we're arriving…' – to narrate images, reflect on the process of her filmmaking, and make theoretical observations about art, life, and theory. She invites the viewers on a journey, often signposting their way, 'now we'll go…'. The voice-over unites the images, directing the viewer on a journey sustained by undercurrents of time passing.

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[213] Adam Phillips, 'Against Biography', Empson Lecture, The University of Sheffield, 2016.

[214] In Godard's two films *Passion* and *Scénario du Film 'Passion'* for example, he describes processes of seeing what is not yet actual.

[215] Michael Taussig, *I Swear I Saw This: Drawings in fieldwork notebooks, namely my own,* Chicago, IL: University of Chicago Press, 2011.

Visual methods, which serve anthropology and ethnography well as ways of observing others, are not commonly employed in autoethnography as methods for investigating personal experience. Perhaps this is less a reasoned exclusion of forms other than writing; rather autoethnographers may be more familiar with the traditional (and institutional) use of writing as a form of enquiry. It may also be explained by an understanding of the therapeutic use of writing, coupled with the practice of using autoethnography to address difficult and traumatic experiences. Expanding autoethnography to include autobiographical art practice in addition to autobiographical writing practices amplifies possibilities for insight and new understanding and this insight is offered as methodological contribution to knowledge.

Doing Autoethnography

Sally Denshire, health practitioner-researcher, citing the political scientist DeLysa Burnier, writes that to ‘do’ autoethnography, it is not possible to ‘feel completely at home in your discipline’.[216]Gillie Bolton, taking an interdisciplinary approach in *Reflective Practice*, distinguishes between reflection and reflexivity. Reflection involves ‘reliving and rerendering’ to illuminate something unnoticed at the time – a detail missed.[217] Reflexivity is a deeper questioning, beyond the level of practical problem-solving, of reasons for what is uncovered through reflection.[218] While acknowledging stories as attempts to order a chaotic world, Bolton writes that reflexivity involves making aspects of the self strange, paying close attention to ourselves and the effect we have on other people, situations, and structures.[219] She likens the process of reflexivity to looking as if from the outside.[220]

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[216] De Lysa Burnier, ‘Encounters with the Self in Social Science Research: A Political Scientist Looks at Autoethnography’, *Journal of Contemporary Ethnography,* 35, 4, 2006, 410–18. Cited in Sally Denshire, ‘Autoethnography’, *Sociopedia.isa,* 2013 <DOI: 10.1177/205684601351> [accessed 28 June 2107].

[217] Gillie Bolton, *Reflective Practice: Writing and professional development* (Second Edition), London: Sage, 2005 [First Edition, London: Paul Chapman Publishing, 2001], p. 9.

[218] Bolton, *Reflective Practice,* p. 9.

[219] Bolton, *Reflective Practice,* p. 10.

[220] Ibid.

Addressing my position in this work – as patient, artist, and researcher – I view the binary of insider/outsider as problematic. My position as patient is not a practice – though there are ways of being good at it – nor is it separable, for it infiltrates everything and there is no objective observer. I adopt and adapt into particular roles, sometimes deliberately and at others times unconsciously; there are also occasions when others project certain roles on me. These shifting positions affect my ability to collect data.

Parker describes reflexivity as a 'way of working with subjectivity in such a way that we are able to break out of the self-referential circle that characterises most academic work'.[221] Parker proposes reflexive activity as a way of attending outwardly to the social relations that enable individuals 'to experience themselves as an individual in relation to others'.[222] He attends to three aspects of research: historical assumptions about what research is and who does it, institutional constraints (which have a bearing on the questions that are asked and who is considered in a position to answer), and the potential impact of personal alliances.[223]

Parker draws on the work of Theodor W. Adorno to show how 'every claim to objective truth is also simultaneously the reflection of the historically-embedded subjective position of the researcher in what they are studying'.[224] Adorno's negative dialectics operates as immanent criticism, pursuing contradictions in reality and turning the language of description against itself to locate truth.[225] Parker advises radical researchers to commit to the ethos of the project in which they are involved, with an awareness that they interpret from a 'specific conceptual frame and sceptical, in and against dominant versions of reality'.[226] When researchers are invited to reflect, this

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[221] Parker, *Qualitative Psychology*, p. 25.

[222] Parker, *Qualitative Psychology*, p. 29.

[223] Parker, *Qualitative Psychology*, pp. 29, 25.

[224] Susan Buck-Morss, *The Origin of Negative Dialectics: Theodor W. Adorno, Walter Benjamin, and the Frankfurt Institute*, Hassocks: The Harvester Press, 1977. Cited in Parker, *Qualitative Psychology*, p. 27.

[225] Theodor W. Adorno, *Negative Dialectics*, translated by E. B. Ashton, New York, NY: Seabury Press, 1973 [*Negative Dialektik*, Frankfurt am Main: Suhrkamp Verlag, 1966]. Cited in Parker, *Qualitative Psychology*, 2005, p. 28.

[226] Parker, *Qualitative Psychology*, p. 28.

may often only occur within ‘taken-for-granted limits that are also set in place by academic institutions’.[227] Despite being required by the system, reflective and reflexive practice is ‘essentially politically and socially disruptive’, encouraging the transgressive use of reflection and reflexivity for change.[228]

Diary Writing

Parker acknowledges the use of a diary in research for recording, reflection, and creating distance.[229] He also writes that the diary can be useful to keep alive the process of making strange the researcher’s findings.[230] A recent experience with a short text in note form that I wrote in Porto gave me a new understanding of the process of defamiliarisation. As I read the text for the first time some four months after I wrote it, I was astonished by what I had written, not recalling writing it. I was not even certain until the end if the main character was male or female. I had written it in haste on an intense period of fieldwork and did not review it. Now I remember exactly the occasion to which I refer and where I use my imagination, building an idea for a sequence of film. The text follows below.

> *Anon. An unburdening*
>
> The end of the journey. Camera tracks alongside the confession boxes. We sit people, women mostly, kneeling – statuesque – at the side of the ornate little confession houses. The bodies barely move but it is just possible to see their lips moving. They whisper.
>
> Shot from the back of the church, we see people walk down the aisle towards the altar; they kneel and make the sign of the cross before sitting on a pew.

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[227] Parker, *Qualitative Psychology*, p. 25.

[228] Bolton, *Reflective Practice*, pp. 1–2.

[229] Parker, *Qualitative Psychology*, p. 27.

[230] Parker, *Qualitative Psychology*, p. 37.

> This kneeling and whispered telling is cut up with another, the protagonist, who moves also down the aisle and towards the altar not stopping but falling into its imagined arms, exhausted depleted and now ready for a telling, knowing full well that no one is here to listen but that makes it about as pure as you can get. No audience to consider. No ethics. No question of ethics to the self.
>
> The shot flicks violently between their kneeling and her falling, collapsing, prostrating. Their telling at the confession box and her wailing.
>
> The man on the train (one of them). He tells me this is not the end. He has done it himself, and he recommends it. They went to the coast and burnt their clothes. This signified a new beginning. Phoenix rising. I wonder was he just trying to get me to imagine him naked. How did I manage to put him off accompanying me across Vigo to the other station?

The distance I have from my written notes allows me to read what I have written with insight. I can now read *Anon. An Unburdening* as making reference to the end of Godard's *Scénario du Film 'Passion',* where he talks of telling when you are in your mother's arms. When I watched this film, these final scenes had a marked effect on me. I felt sad, thinking of the times as a child (and as an adult) when my mother held me if I was sad. *Anon. An Unburdening* is set in the church in Santiago de Compostela, a place of pilgrimage that I visited for a day. I also write about a man I met on the train on my return journey to Porto. I am amused by this last part.

Bolton advocates writing a reflective journal – a learning journal – that she views as a support structure for reflection as opposed to a finished product.[231] She differentiates between a log (a straightforward record of events, useful as an aide-mémoire), diaries that can contain anything including creative material, and journals – 'records of events, thoughts and feelings about a particular aspect of life, or with a particular structure'.[232]

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[231] Bolton, *Reflective Practice*, p. 163.

[232] Ibid.

A journal can pertain to anything, recording it in any way that is appropriate.[233] Bolton distinguishes a reflective practice journal as one that includes deliberate thinking and analysis about one's practice.[234]

Tarkovsky's diary, *Time Within Time,* is comprised of notes, occasional sketches, poems, letters, and lists.[235] The diary does not address the reader, appearing to be written for Tarkovsky himself – which makes me feel uncomfortable reading it. Tarkovsky's entries always begin with the date and place and his entries cover many topics. Often he writes directly about the work in which he is involved – the progress of his films and his relationships with others in the industry. These writings flow into considerations of potential projects and ideas – what could be.

Time Within Time is often now read, or at least written about, in terms of what it tells not only about Tarkovsky, but also about the times in which he was filmmaking – a shoot in Buenos Aires, for example.[236] It is considered as offering insights into a culture. Kitty Hunter-Blair in 'A Note from the Translator' remarks that Tarkovsky often quotes Hermann Hesse, including the following: 'every man is not only himself; he is also the unique, particular, always significant and remarkable point where the phenomena of the world intersect once and for all and never again'.[237] The tone of the entries varies: At times, it is humorous – in one entry, Tarkovsky writes that he got drunk and did not realise he had shaved off his beard until the following day.[238] In other entries the tone is sad as Tarkovsky reflects on life.

Tarkovsky writes about his health when he feels bad and exhausted.[239] In his 1985 entries, he writes he is suffering from 'severe bronchitis'.[240] He writes of having his X-

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[233] Bolton, *Reflective Practice*, p. 164.

[234] Mary Louise Holly, 'Reflective Writing and the Spirit of Enquiry', *Cambridge Journal of Education,* 19, 1, 1988, 71–80, p. 78. Cited in Bolton, *Reflective Practice*, p. 164.

[235] Andrey Tarkovsky, *Time Within Time: The Diaries 1970-1986,* translated by Kitty Hunter-Blair, London: Faber and Faber, 1994 [*Мартиролог : gневники 1970-1986,* Frankfurt: Ullstein, 1989].

[236] Tarkovsky, *Time Within Time*, p. 77.

[237] Tarkovsky, *Time Within Time,* 'A Note from the Translator, Kitty Hunter-Blair', p. vi.

[238] Tarkovsky, *Time Within Time,* p. 6.

[239] Tarkovsky, *Time Within Time,* pp. 44, 65, 68, 69, 82,129.

rays sent to the specialist, as he was coughing blood.[241] From here on, his entries relate more and more to feeling ill as he wonders what is the matter with him.[242] He learns he has a lump in his lungs and head.[243] On 15 December, Tarkovsky writes:

> Throughout his life a person knows that sooner or later he is going to die, but he doesn't know when. And to make it easier to live his life, he relegates that moment to some indefinite point in the future. But I do know, and nothing now is going to make it easier for me to live. That is very painful; but worst of all is Larissa—how am I going to tell her? How can I, with my own hands, inflict that appalling blow on her?[244]

Tarkovsky's entries for the year 1986 cover two pages. He writes from a clinic in West Germany. It makes me very sad to read these last entries.

My diary writing serves multiple purposes and I write notes in clinic appointments to remember important information (as I have always done as a patient). On such occasions I am acutely aware of my position as artist and researcher; driven by practice, I am also engaged in fieldwork.

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240 Tarkovsky, *Time Within Time*, p. 342.

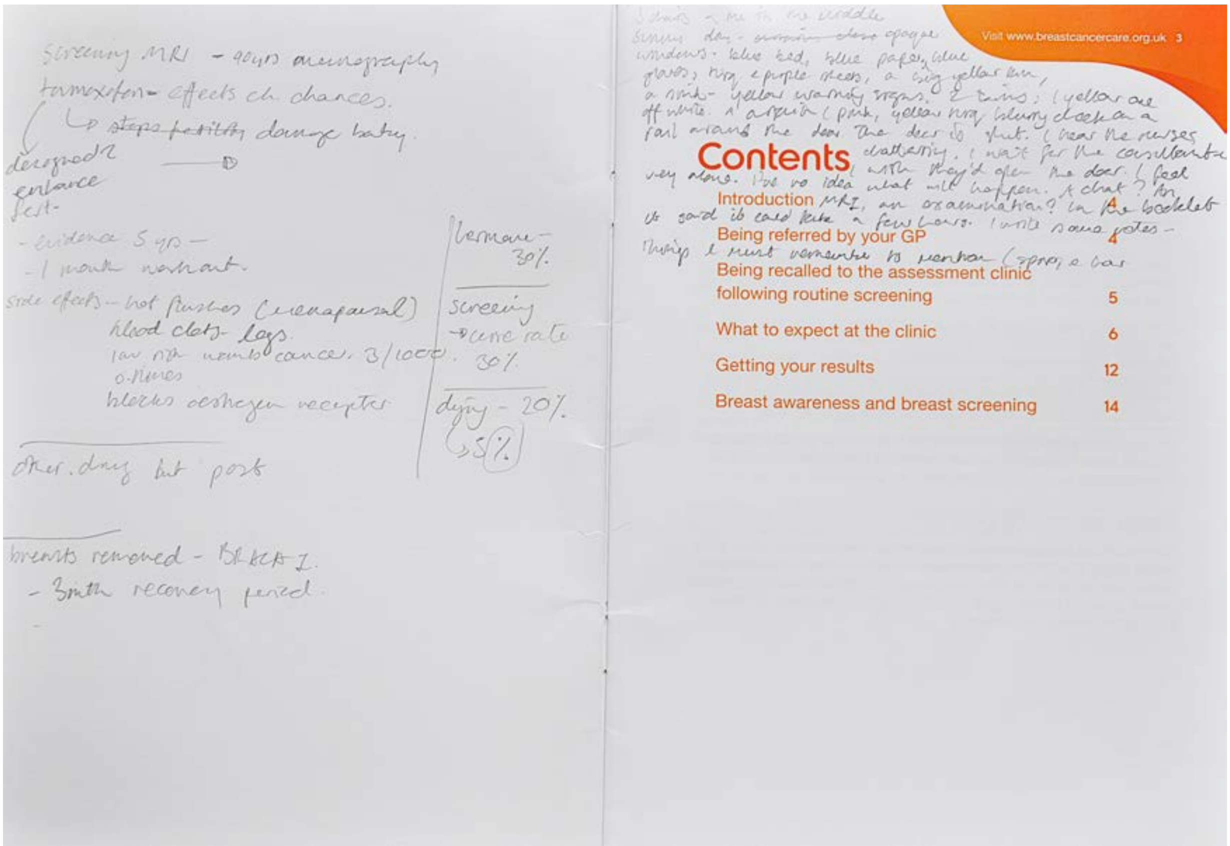
[241] Tarkovsky, *Time Within Time*, p. 346.

[242] Tarkovsky, *Time Within Time*, p. 348.

[243] Tarkovsky, *Time Within Time*, p. 348.

[244] Tarkovsky, *Time Within Time*, p. 349.

Figure 1



Screening MRI – 40yrs mammography
tamoxifen – effects ch. chances.
↳ ~~stops fertility~~ damage baby.
decreased
entrance
test-
- evidence 5 yrs –
- 1 month warrant.
side effects – hot flushes (menopausal)
blood clots – legs.
low risk womb cancer. 3/1000.
o.times
blocks oestrogen receptor

[illegible] – 30%.

screening → cure rate 30%.

dying – 20%.
↳ 5%

other. drug but post

breasts removed – BRCA 1.
- 3mth recovery period.

Visit www.breastcancercare.org.uk 3

Contents

[illegible] me in the middle
Sunny day – ~~[illegible]~~ close opaque windows. blue bed, blue paper, blue gloves, [illegible] purple sheets, a big yellow bin, a pink-yellow warning signs. 2 bins: 1 yellow one off white. A [illegible] (pink, yellow ring) blurry clock on a rail around the door. The door is shut. I hear the nurses chattering. I wait for the consultant with [illegible] they'd open the door. I feel very alone. I've no idea what will happen. A chat? An MRI, an examination? In the booklet it said it could take a few hours. I write some notes – things I must remember to mention (spray, a bar

Notes made during a recent hospital visit

Reflection on this practice of writing enables me to write about how I investigate myself – as artist, patient and researcher – and how this relates to my art practice. These text and image based reflections are, alongside my primary notes, incorporated into work.

> 23rd April 2015
>
> Yesterday I had an appointment at the breast clinic. My appointment was early, I woke up tired, had a quick breakfast and coffee and walked to the Royal Hallamshire hospital. I walked past the plaque bearing the Medical School motto 'ARS LONGA, VITA BREVIS'.
>
> After a little detour, I arrived at the correct reception where the correct receptionist took a note of my arrival and asked me to take a seat. I made a mental note of the number of people in the waiting room. There were about seven, I was probably the youngest, and there were only two of us alone. Nurses milled around

and chatted. I sat down and then got up to take some literature from a table. I had an inkling that I was in for an MRI and scanned the booklet: ‘What to expect from your appointment’. There was no mention of MRI, only mammography and biopsy. It said the appointment could last several hours. I wondered what the hell they would do. I wasn’t sure if this was the type of appointment I was having.

A nurse approached me and said the consultant was on her way but hadn’t arrived yet. I got up again and looked around for something more informative to read.

A cheery nurse called my name and I followed her down the corridor, she was friendly and told me her name before asking me to sit in a room and wait for the consultant. She closed the door.

I could hear the nurses chatting outside and managed to successfully stop a recurring thought about being alone. I wondered whether it was good practice to shut the door. I wanted to open it. Instead, I took a pencil from my bag and described the room, scribbling on the empty space in the booklet. I imagined that the booklet designers had left space for exactly this purpose. I was very detailed. This would be used later, either in my diary entry, or as material for work. The consultant came in and introduced herself as a surgeon. I had no idea I was seeing a surgeon.

When the 45-minute appointment was over, I was asked to wait outside on a seat in the corridor. I was given a prescription and took it to the pharmacy. On the way, I noticed a pattern of lines on the floor and secretly filmed myself walking these lines with my phone. I wish I had free access to make a film in a hospital. Godard said that his film of the factory workers, whom he filmed on holiday, was political.[245] It was not possible for them to film in their workplace, thus the act of filming holidays was a political act. A good strategy, to work with what I have, and of course what I don’t have, show, or say, is most important.

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[245] *Vive le cinéma - la politique et le bonheur: Goerges Kiejman et Jean-Luc Godard*, Réalisé par Jean-Luc Godard, 1972.

As well as diary writing, I write to reflect on works, engage with texts, explore and formulate ideas, record meetings and interviews, write academic papers, and communicate my research. I explore different forms, structures, purposes, functions, and genres.

Making Reflection

Reflection is part of my research process: I learn while making and through reflection on my making. Schön encourages reflection in different ways: 'Reflection-in-action' acknowledges the intuitive, improvisational, and often tacit knowledge of the practitioner while doing;[246] it involves thinking about what is being done and reshaping action while doing it. 'Reflection-in-action' relies on feeling, response, and adjustment. Schön likens it to conversation, suggesting that designing, for example, is a 'reflective conversation with the materials of a situation'.[247]

Psychotherapist Kenneth Wright defines attunement, which accounts for mother–infant relatedness,[248] in the words of Daniel Stern as: 'a recasting of an affective state'.[249] To her child, an attuning mother (a usually continuous state) reflects the feelings of the child – as experienced by the mother – back to the child, momentarily after her/his experiencing them.[250] Attunement does not rely on the mother's mimicry, rather the mother's living through experiences with the child enables the her, through identification, to portray the shape and rhythm of the child's 'inner state, at least as she has perceived it'.[251] Wright suggests that this process be viewed as reflective improvisation.[252] The mother's repertoire of responses is not fixed as she responds

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[246] Donald Alan Schön, *The Reflective Practitioner: How Professionals Think in Action,* New York, NY: Basic Books, 1983, p. 308–309. Cited in Gray and Malins, *Visualising Research*, p. 22.

[247] Schön, *The Reflective Practitioner,* p. 78. Cited in Gray and Malins, *Visualising Research,* p. 22.

[248] Daniel N. Stern, *The Interpersonal World of the Infant,* New York, NY: Basic Books, 1985, pp. 138–61. Cited in Kenneth Wright, 'The Shaping of Experience', *British Journal of Psychotherapy*, 21, 4, 2005, 525–41, p. 535.

[249] Stern, *The Interpersonal World of the Infant*, p. 161. Cited in Wright, 'The Shaping of Experience', p. 535.

[250] Wright, 'The Shaping of Experience', p. 535.

[251] Wright, 'The Shaping of Experience', pp. 535, 539.

[252] Wright, 'The Shaping of Experience', p. 540.

creatively to her child.[253] Wright concludes that the interaction between mother and child – a dialogue or echo – yields a new structure, which is felt but not yet known, 'available but not yet not thought about'.[254] Wright suggests that containing structures are formed through the mother–infant dialogue of attunement, a process, which he brings to bear on how we communicate the feel of experience through concrete presentational forms.[255] Something of the process of attunement, as described by Wright, is shared with Schön's 'reflection in action' and indeed my own making.

Personal Narrative

The study of personal narrative arose as an alternative to traditional ways of studying humans that, as Parker writes, neglect the meaning that people gave to their own lives.[256] In social science research, biographical narratives, which encompass relatively long periods of life, are often studied in relation to questions of identity and its performance.[257] Ellis writes:

> Personal narratives propose to understand a self or some aspect of a life as it intersects with a cultural context, connect to other participants as co-researchers, and invite readers to enter the author's world and to use what they learn there to reflect on, understand, and cope with their own lives.[258]

I conduct structured analyses and close readings of existing patient narratives and critiques of narratives, enquiring how authors cast illness in their narrative, familiarising the reader with patient narratives, and contextualising my work in the field of patient narrative. In so doing, I investigate how narrative is used as a tool in illness, particularly genetic medicine.

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[253] Ibid.

[254] Ibid.

[255] Wright, 'The Shaping of Experience', p. 525.

[256] Parker, *Qualitative Psychology*, p. 71.

[257] Parker, *Qualitative Psychology*, p. 78.

[258] Ellis, *The Ethnographic I*, p. 46.

My approach to this analysis is one of principled eclecticism, allowing the exploration of the narratives featured through a range of lenses that would not be possible within any one paradigm of analysis. My reading is inflected by how other researchers analyse texts and artists working with narrative and text. I consider what makes a good reader of a patient narrative.

My readings of extant patient narratives also facilitates my discovery of aspects that I explore through making work, enhancing my understanding of different approaches to narrative.

I attend patient narrative training, analysing my experience thereof through my textual and visual work. This drives my use of art practice to reveal elements of my experience that resist narration through the restrictive language and formulaic structure so often associated with patient narratives.[259]

I investigate the documentation of personal narrative and its status as a method. Any inconsistency between the experience and its narration is considered as a possible and productive fiction, explored in terms of its ability to further understanding of the self (as an accounting of subjective experience delivered to an other/others). Fredric Jameson writes of narrative as 'the imaginary resolution of a real contradiction'.[260] Robin Collingwood writes of 'the constructive imagination'.[261] Paul Ricoeur writes of the imaginative or fictional element of narrative as a defining characteristic of history and fiction. Thus, the role of the imagination – for both narrator and narratee – is viewed as a necessary element in the construction of narrative.

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259 Pilgrim Projects, *Patient Voices,* 2016 <http://www.patientvoices.org.uk> [accessed 28 June 2107].

260 Fredric Jameson, *The Political Unconscious: Narrative as a Socially Symbolic Act,* London and New York: Routledge, 2002 [London: Methuen, 1981], p. 62.

261 Robin George Collingwood, *The Idea of History,* Oxford: Oxford University Press, 1946, pp. 239–41.

In an interview with Brian Catling, Hayley Newman speaks of the fictional quality of narrative as a smoothing over.[262] Newman says this in relation to her work *Connotations – Performance Images 1994–98,* the photographic and textual documentation of twenty-one fictional performances, staged and performed by Newman and photographed by photographer and collaborator Casey Orr.[263] Accompanying text panels give minimal details about each of the works – description, title, dimensions, medium, date, and associated information. However, when exhibited, a disclaimer, which says Newman has not done any of the works, usually accompanies the work. Like a hall of mirrors, says Newman, it is hard to know what is real and what is not – everything seen in the photographs had to be done for the photographs to exist at all, but the accompanying texts describe something different.[264]

In *Crying Glasses (An Aid to Melancholia)* (1995) Newman is photographed in a carriage on the London Underground wearing dark sunglasses. Tears (glycerine) stream down Newman's cheeks. The text panel describes a pump system in Newman's glasses: as an aid to melancholia, the pump system enables Newman to cry publicly when she is melancholic.[265] *Crying Glasses (An Aid to Melancholia)* (1995) weaves biographical details and fiction: photographed over one week in London in 1998, Newman claims that it was performed over four years (1994-1998) in several countries – those she had visited that year. Newman speaks of the work as a form of autobiography in a history of performance with explicit reference to the artist Adrian Piper's work *Catalysis IV*.[266] Newman says that making these connections – between performance history and her

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[262] Hayley Newman is interested in subjectivity, documentary, performance, fiction, and the exploration of how collectives and individuals function, University College London, Slade School of Fine Art, *Dr Hayley Newman, Teaching Summary* <http://www.ucl.ac.uk/slade/people/academic/profile/HJENE78#teaching-summary> [accessed 28 June 2107].

[263] Works in the series include: *I Spy Surveillance Fly* (1994, Photograph, 38.5 x 38.5 cm); *Lock-Jaw Lecture Series* (1997-8, Photograph, 45.5 x 36 cm); *You Blew My Mind* (1998, Black and white photograph, 91 x 92.5 cm); *B(in)* (1996, Photograph, 39 x 39 cm), and *Crying Glasses (An Aid to Melancholia)* (1995, Photograph, 50 x 40 cm).

[264] *Interview with Hayley Newman by Brian Catling,* 2012 <http://vimeo.com/42560087> [accessed 28 June 2107].

[265] *Interview with Hayley Newman by Brian Catling,* 2012 <http://vimeo.com/42560087> [accessed 28 June 2107].

[266] Adrian Piper's *Catalysis series* (1970-73) is a series of conceptual performance works that take place in Manhattan, New York. In *Catalysis IV,* Piper is photographed on the subway with a white towel stuffed in her mouth. Next to her, a woman wearing large dark glasses turns away. In *Crying Glasses (An Aid to Melancholia)* (1995) Newman wears an almost identical pair of dark glasses. *Interview with Hayley Newman by Brian Catling,* 2012 <http://vimeo.com/42560087> [accessed 28 June 2107].

own history – requires a form of narrative. In this way, she speaks of narrative as a smoothing over, and therefore fictionalisation.[267]

Jurecic considers patient narratives as imperfect but necessary fictions. [268] Extant patient narratives often reveal the construction of a clear beginning, middle, and end through a literal or metaphorical journey. I explore this in my narrative formation as well as that which evades the 'smoothing over'.[269]

I explore the status (itself a matter of rhetorical construction) of the material that informs my narrative construction – medical evidence, recorded conversations, hearsay, second-hand news, stories heard and over-heard, interviews, travel documents, medical records, events witnessed, mythologies, and stories that I hear about other patients, first-, second-, and third-hand.[270]

My Quest Narrative

In June 2006 I had my stomach removed. I spent ten days in Leeds General Infirmary before I was discharged. Later I received a letter telling me that the beginnings of cancer had been found in my stomach. The letter, which I have lost, carried a postmark from Portugal. In May 2014 I planned a trip to Lisbon to give my first paper at a conference on narrative.

I had been reading Frank's *The Wounded Storyteller*, thinking about storytelling as a transformative vehicle by which the ill person might begin narrative reconstruction,

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[267] *Interview with Hayley Newman by Brian Catling,* 2012 <http://vimeo.com/42560087> [accessed 28 June 2107].

[268] Jurecic, *Illness as Narrative,* p. 42.

[269] *Interview with Hayley Newman by Brian Catling,* 2012 <http://vimeo.com/42560087> [accessed 28 June 2107].

[270] I heard that one gastrectomy patient keeps their stomach in their house and that another has named their now removed stomach. I read about other patients in newspapers and magazines and then I meet them at events ran by Cambridge University Hospitals, where patients share their experiences and those of others. I recount to inquiring others the surgical procedure undertaken to remove my stomach and later, I hear the surgeon tell a different story. I receive a letter from Porto telling me the pathology lab has discovered little bits of early cancer in my removed stomach, but cannot find the letter or a record of there ever having been one. Nurses' comments on my medical records do not tally with my memory of events. I am interviewed for research but find I do not give a full account 'on record'.

have agency and heal. I thought about autobiography, and wondered wherein lies patient narrative.

I made notes on the three narrative plots Frank proposes for this purpose: the restitution narrative, the chaos narrative, and the quest narrative.[271] I was drawn to Frank's idealising of the quest narrative. I wondered what it would mean to be transformed, and felt driven to create a monomyth and star as the hero in my own story. Elevating the status of the individual patient to one of agency, I assigned myself the role of hero, rather than my diagnosis and resultant surgery or my doctor.

I make work by interrogating the structure of the quest narrative. Embracing and critiquing the trope of the journey, I begin the quest to trace my stomach. I travel to Lisbon. Taking the yellow line under the city, arriving at the Santa Maria hospital campus in the pouring rain, dashing across the car park to the Egas Moniz building and the Instititut o de Medicina Molecular. A security guard prevents me from entering; telling me filming is prohibited. I sneak my DSLR under my jacket, as much to protect it from the rain, and film, in secret.

I perceive the quest as a conceptual method. Like a private detective or investigative journalist, I am an instrument of my research. My position might be viewed as distinct from that of an autobiographer, for example, who is seldom thought to live through experiences for the sole purpose of writing about them autobiographically.[272] I reflect on my role and how I feel accountable to the quest, which adds a reflective layer to the work I make.

My quest narrative has entailed travelling to Portugal twice, to Lisbon and Porto, and to Cambridge, England once, to search for my stomach: travelling is a method and I

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[271] Frank, *The Wounded Storyteller,* 1995, p. 75.

[272] Jerome Bruner, 'The autobiographical Process', in *The Culture of Autobiography: Constructions of Self-representation,* edited by Robert Folkenflick, Stanford, CA: Stanford University Press, 1993, pp. 38–56; Norman K. Denzin, *Interpretive Biography,* Newbury Park, CA: Sage, 1989; Mark Freeman, 'Data are Everywhere: Narrative criticism in the Literature of Experience', in *Narrative Analysis: Studying the Development of Individuals in Society,* edited by Colette Daiute & Cynthia Lightfoot, Thousand Oaks, CA: Sage, 2004, pp. 63–81. Cited in Ellis, Adams, and Bochner, 'Autoethnography: An Overview', p. 2.

scrutinise the ingredients of travel. For these journeys, and in a similar way to Sharon Kivland, who reconstructs, re-traces, and re-imagines Freud's journeys in her book series *Freud on Holiday*,[273] I construct travel itineraries, plans, and write funding requests. I collect correspondence with insurance companies, travel tickets, playlists, postcards, mementos, objects (dried flowers, shells, charms, Saint Christopher medals, and so on), maps, records of what I pack (books, toiletries, clothes), business cards, brochures, reflective travel journal writing, and other travel ephemera; newspaper clippings, exhibition catalogues, hospital letters, personal letters, photographs, short stories, lists, prescriptions, stamps, and drawings. I capture still and moving images. I record conversations I have with people at home while I am away, when we reflect together on my days' events, how I am feeling, the difficulties of the quest, what is going well, and the plans I have. I document everything, including the days when I cannot document – when my languages fail and on days when things go wrong. Later, I use this material – core research data – in my making.

Befriending

The transitive verb 'to befriend' means to behave in a friendly manner, or to become a friend to someone, especially when that person needs help. I use the term befriending to describe my interactions with others, differentiating my method from interviewing through emphasising the import of relationships.

Gathering material for my narrative formations entails interaction with others; my quest narrative, for example, with people who I believe might assist me trace the whereabouts of my stomach. These interactions – with friends, family, academic and artist colleagues, doctors, nurses, pathologists, geneticists, and scientists – are either quotidian or a consequence of pre-arranged meetings and take place in person, *via* email or telephone. Reflecting on these interactions feels more like reflecting on relationships

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[273] Sharon Kivland, *Freud on Holiday, Freud Dreams of Rome*, York: Information as Material, I, 2006; Sharon Kivland, *Freud on Holiday, A Disturbance of Memory*, Athens and York: Information as Material and Cube Art Editions, II, 2007; Sharon Kivland, *Freud on Holiday, The Forgetting of a Proper Name,* Athens and York: Information as Material and Cube Art Editions, III, 2011; Sharon Kivland, with Lucia Farinati, *Freud on Holiday, A Cavernous Defile – Part I,* York: Information as Material, and Athens: Cube Art, IV, 2013.

I have established. In my interactions, I feel on an equal footing with those to whom I speak. We share our aims and thoughts about many things, asking each other questions in a way that is not a feature of interviews, which are more unidirectional. The term befriending challenges power relations that are commonly thought to exist in doctor/patient, researcher/researched relations.

Ethical Considerations

Ethical considerations are fundamental to this work, not only as they apply to the procedures that enable it, but as a vital guide for navigating my doctoral work. My Ph.D. is contingent on ethical approval from Sheffield Hallam University's Research Ethics Committee. Approaches to research based on procedural ethics face criticism. Kristian Pollock, Principal Research Fellow in the Faculty of Medicine and Health Sciences at Nottingham University, writes about the limitations of procedural ethics, suggesting a disparity between qualitative approaches to research and the bioethical basis of current practice in procedural ethics. While not doubting the necessity of regulatory frameworks, Pollock writes:

> The standard formulas and oversimplified rules prescribed for research conduct appear to offer solutions whilst eliding the real issues, from the quotidian to the exceptional, to be encountered in real world research. Far from promoting ethical research it has been argued that the rigidity of procedural ethics is deskilling.[274]

Current governance places the qualitative researcher in an invidious position, caught between formal requirements of ethical approval which may not incorporate understanding of the pragmatics of fieldwork or the concerns and interests of participants on the ground, and the – equally 'ethical' – requirement to maximise the scarce opportunity to deliver best quality research with findings that may offer real impact and benefit to patient care.[275]

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[274] Kristian Pollock, 'Procedure versus Process: Ethical Paradigms and the Conduct of Qualitative Research', *BMC Medical Ethics,* 13, 25, 2012, p. 7 <http://www.biomedcentral.com/1472-6939/13/25> [accessed 28 June 2107].

[275] Kristian Pollock, 'Procedure versus Process', p. 7.

While I acknowledge Pollock's concerns about procedural ethics, my experience of procedural ethics, far from deskilling my ethical capacity as a researcher has had some positive consequences. The discussion and deliberation that occurs as I navigate procedural codes and ethical regulations opens up questions in my research rather than closing it down. Navigating procedural ethics provides me with a basic structure in which I am repeatedly required: to communicate my work to others from different disciplinary backgrounds; to articulate how I conceive of each of my actions as research activity; to familiarise myself with the different definitions of research between and within disciplines; to consider how my articulations of my work can take a different form and content depending on with whom I am communicating – I reflect on the ethics of this chameleon researcher.

However, the impact of procedural ethics on this research is not wholly positive. My concern to work ethically, while driving the discussions described above, can have a limiting effect on my research, as I am extremely cautious not to act in an unethical way. Paying due care to others influences how I conduct my research and the shape of the project. My consideration for the wellbeing of others facilitates professional, caring, mutually beneficial, and often enjoyable contact with others. Yet, my consideration for others, on occasion, renders my practice tentative: I could ask more of people (time, information, sound recordings, written feedback, and video footage), which would provide me with more material with which to work. However, the tentative and sensitive aspects of my work are integral to my practice and, it is unlikely that I would incorporate additional material of this sort into my work. Furthermore, in following this bolder route, I may not nurture such close relationships, which undoubtedly play a vital role in facilitating research through my data collection: participants are incredibly open and generous with me.

Autoethnographic Practices and An Ethics of Self-Care

Much of the literature about ethical considerations in autoethnographic research concerns relational ethics. Ellis, for example, writes: 'researchers do not exist in isolation. […] Consequently, when we conduct and write research, we implicate others in our work.'[276] Professor of Education Heewon Chang reminds autoethnographic researchers that 'as you play a multi-faceted role as researcher, informant, and author, you should be reminded that your story is never made in a vacuum and others are always visible or invisible participants in your story'.[277] In the early stages of this research, Dr Peter Allmark, Principal Research Fellow at Sheffield Hallam University gave me the University of Sheffield's Specialist Research Ethics Guidance Paper – 'Ethical considerations in Autoethnographic Research', written by Professor Pat Sikes, Professor in Qualitative Inquiry at Sheffield University – for ethical guidance.[278] Martin Tolich's (a specialist in the Sociology of Research) ten guidelines for the ethics of autoethnographic research, inform the University of Sheffield's Specialist Research Ethics Guidance Paper. Tolich's guidelines, drawing on multiple sources and representing much of the literature on ethics and autoethnography, focus on consent, consultation, and vulnerability.[279]

A neglect of ethical consideration for the autoethnographer her-/himself in the literature is striking. Autoethnography, despite its humanist foundations, has little to say about self-care, particularly troubling as autoethnographic work commonly concerns difficult issues including vulnerably and trauma. This echoes Hallowell's finding (cf. Chapter One) that fundamental to women's decision-making around genetic testing is the placement of the needs of others before their own.[280] Hallowell writes about the influence of gendered discourses, which position women – particularly mothers – as responsible for the care of others, on women's justification of their behaviour in her study.[281] The work of the Wages for Housework Campaign, Helen Hester, Silvia Federici, Selma James, and Mariarosa Dalla Costa (as well as many others) on

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[276] Ellis, Adams, and Bochner, 'Autoethnography: An Overview' p. 1.

[277] Heewon Chang, *Autoethnography as Method,* Walnut Creek, CA: Left Coast, 2008, p. 69.

[278] Pat Sikes, Specialist Research Ethics Guidance Paper, Ethical considerations in Autoethnographic Research, 2015 <https://www.shef.ac.uk/polopoly_fs/1.586562!/file/SREGP-Autoethnography-2015.pdf> [accessed 28 June 2107].

[279] Martin Tolich, 'A Critique of Current Practice: Ten Foundational Guidelines for Autoethnographers', *Qualitative Health Research,* 20, 12, 2010, pp. 1599–610.

[280] Nina Hallowell, 'Doing the right thing: genetic risk and responsibility', *Sociology of Health and Illness,* 21, 5, 1999, 597– 621. Cited in Kerr, *Genetics and Society,* p. 94.

[281] Hallowell, 'Doing the right thing: genetic risk and responsibility', p. 616.

reproductive labour provides a context for Hallowell's gendered findings. This deserves recognition especially in light of the work of Deborah Lynn Steinberg, who argues that a consequence of the construction of women by gendered genetic discourses as 'the bearers of "nature's defects"' or 'gene transmitters' is the perception of women as solely responsible for passing on their genes and their partner's genes.[282]

Each autoethnographic study has its own ethical quandaries which are not anticipated despite careful preparation and due attention. In the third year of my Ph.D., I became increasingly aware of the need to consider my own welfare – as researcher and researched. My focus on others (echoing the literature on autoethnography and the focus of procedural ethics) may have contributed to a neglect of my own welfare and wellbeing. I had not considered the potential effects of using myself as an instrument in an extended piece of research focused on illness. Particularly pertinent was the time I spent in Porto on a quest to locate my stomach. Exploration of reflective and mirrored surfaces is important in my image making. Porto is one of the most reflective cities I have visited. What should have been a perfect opportunity for making spiralled into a difficult few weeks as I struggled to confront the weak, thin self reflected back at me, echoing research findings that body image is reported as a significant issue faced by prophylactic gastrectomy patients.[283]

As Pollock writes, the complex and shifting nature of real world settings delivers unanticipated ethical issues and (occasionally) genuine dilemmas, which go beyond easy or formulaic 'procedural' resolution.[284] I faced genuine dilemmas including when to be a researcher and when not (how to negotiate time off) and how to overcome the challenges of retelling – a fundamental part of much artistic work. In many ways, this is no different for many artists, yet in my experience it remains largely un-discussed, with conversations limited to those between friends and confidants.

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[282] Deborah Lynn Steinberg, 'Languages of risk: genetic encryptions of the female body', *Women: a Cultural Review*, 7, 1996, 259–70, p. 267. Cited in Hallowell, 'Doing the right thing: genetic risk and responsibility', p. 599.

[283] Elizabeth Worster, Xinxue Liu, Susan Richardson, Richard H. Hardwick, Sarah Dwerryhouse, Carlos Caldas, Rebecca Fitzgerald, 'The Impact of Prophylactic Total Gastrectomy on Health Related Quality of Life: A Prospective Cohort Study', *Annals of Surgery,* 260, 1, 2014, 87–93.

[284] Pollock, 'Procedure versus process'.

In hindsight, certain practical considerations would have made this period of autoethnographic work safer for me, as both researcher and researched. I would now advocate the following: structuring time to include strictly differentiated periods of work and non-work; having a local contact and agreed regular contact with someone, perhaps over the telephone, willing to act in a supervisory capacity; and organising a full debrief after the period of work. [285]

Despite the difficulties of this period of fieldwork – my quest – it was generative, if in unexpected ways. On returning, I realised that I must re-think my approach to my work, both to being a patient and my lifestyle generally to enable me to continue in a healthier manner. This led to a general prioritising of self, which resulted in improved overall wellbeing and an increased ability to research. Specific interventions included: a period of counselling provided by SHU Wellbeing Service; an NHS programme to support reducing my painkiller intake; general self-care – adequate sleep, healthy eating, fresh air, yoga practice; stopping smoking, and regular breaks from work. While I acknowledge that this is common sense and not particular to autoethnographic research (especially for doctoral students), it is largely missing from the literature on autoethnography, despite its focus on vulnerability and fragility.

On the other hand, for some people, exposure to risk is seen as a necessary part of their work.[286] In all cases, I advocate a consideration of an ethics to the self. To what extent this is practically taken into account in working practices is for each person to decide. What is important is its presence in academic discourses, and those relating to other relevant working and learning environments. To achieve this, I have used my experiences to create a concrete proposal in the form of a self-contract – *Muito Frágil: A Self-Contract* –, which can be found in Appendix Three as well as in the

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[285] However, embedding this kind of support – which, like the conflated space between artist, researcher and patient, occupies a space between academic supervision, health and safety project management, and student services – may not be practicable in so far as it only exists in separate spaces. Perhaps the work (its editing and review) itself might offer this space.

[286] Chris Kraus, Eileen Myles, Kathy Acker, Sophie Calle, Marina Abramovic, Ana Mendieta, Bas Jan Ader, Ulay, Chris Burden, ORLAN, Francis Alÿs, Pedro Reyes, Ruth Proctor, Ai Weiwei, Pussy Riot, Cosey Fanni Tutti, Bob Flanagan, Jo Spence, Sheree Rose, Steven Kurtz, Simone Aaberg Kærn, Gillian Wearing and many other artists.

accompanying body of art work entitled *Pé de Grue*. I am developing the scope and content of this self-contract through meetings and discussions with others who share similar concerns.

I am exploring how an ethics of self-care might inform new guidelines for autoethnographic practice. Further work must be undertaken if an ethics to the self is to become more visible in autoethnographic research. To stimulate discussion in the field, it will be pertinent to write an article about the period of fieldwork undertaken on my quest narrative, submitting this to the following journals: *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, *Journal of Contemporary Ethnography*, and *Qualitative Inquiry*. I will also write a joint paper with Professor Pat Sikes, Professor in Qualitative Inquiry at Sheffield University – the author of the 'University of Sheffield's Specialist Research Ethics Guidance Paper'.

Image, Capture, Edit

Johannes Sjoberg and Jenny Hughes write that regardless of discipline, practice as research 'privileges action as a methodological imperative'.[287] Art practice as research involves exploring, testing, and extending methods across contexts – examining the relation of art interventions to making and understanding the world.[288]

I capture images with my digital Nikon D90 camera, a gopro, my iPhone camera, and lightweight Manfrotto tripod. Early experiments with two professional video cameras, a Bolex, and a heavy tripod were not carried forward into my practice – the equipment was heavy and bulky and did not travel easily. Although I liked the aesthetic quality of the Bolex (16mm film) and the use of physical, tangible film, the aesthetic – reminiscent of a different era – was not right for my work. This experimentation lead

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287 Johannes Sjoberg, and Jenny Hughes, Methods at Manchester, Resources, *Practice As Research,* methods@manchester, CMIst, The University of Manchester, Manchester <http://www.methods.manchester.ac.uk/resources/categories/qualitative/practice/> [accessed 28 June 2107].

288 Sjoberg and Hughes, *Practice As Research* <http://www.methods.manchester.ac.uk/resources/categories/qualitative/practice/> [accessed 28 June 2107].

me to change the frame rate on my Nikon D90 to 24 frames per second to produce an aesthetic quality closer to film, and I also investigated using different lenses.

When capturing moving image on my Nikon outside, I am often on foot – usually in unfamiliar places. I am less distracted by quotidian worries and so my eyes are keener to see what is around me. I carry my camera in my bag and generally do not have a plan about what I want to film although I may know the area where I want film and have a sense of the images I want to capture. When I see something that I find interesting, I take out my camera and start filming. I film for the full duration that my camera allows – five minutes. Often I am moving when filming though I do not have a steadycam. When I first look through the camera lens, I fix the settings and do not change them during the shot – regardless of whether I am still or moving – and so often my images move in and out of focus. This is purposeful: the blur is significant in my narrative formation. If I am conscious of other people, I hold the camera to my chest and film without looking through the lens. I use the tripod mostly to capture scenes in nature where there is stillness and movement and I feel a time passing differently. My camera also records sound and much of the sound in my work is synch-sound.

I capture moving image on my Nikon when travelling in buses, cars, aeroplanes, and most often in trains. I look through the lens of the camera, fix the settings, and film for the camera's five-minute capacity. I film what I see as I gaze out of the window: the exterior landscape and the reflection on the window – which often incorporates the window opposite and its reflection. Sometimes, I position the camera next to me to capture me in the foreground with the window behind me.

When inside – in my home, churches, hospitals, hotel rooms – my way of filming is different from when I am outside. I am more still, observing detail around me. I pay attention to shapes and colour. Moving the camera to change the distance between what I am filming and me, as well as manually changing the focus, I capture blurred images. I look through the lens to see what I want to capture (when I am outside, I use my eyes). Often the moving image I capture indoors is abstract, textured, and coloured. If there is movement, the pace is much slower than when I am outdoors. I am also more likely to set up the tripod and film myself.

When I am in hospitals for an appointment, if I film (normally I do not on ethical grounds) I use my iPhone camera. I film myself in toilets and changing room mirrors. I also make sound recordings using the voice recorder on my iPhone. I video my feet when I am walking to and through the hospital – this began as a way of capturing something that would not violate ethical principles. Filming on these occasions also functions as a means to protect myself. During a winter holiday to Fuerteventura, I recall being driven to a beautiful vantage point. As we drove up an extremely steep and dangerous track, overcome with fear, my palms were clammy and I could not speak, I took out my camera and filmed. Looking through the lens allayed my fear. Although counterintuitive, my attention to detail – in writing and filming – to hospital waiting rooms, changing rooms, toilets, and entrances brings me closer to that reality while distancing me from it.

I use a Go-pro to film for longer durations than my Nikon allows, when I do not want to be seen with an obtrusive camera, and for filming underwater. It is not possible to look through the Go-pro lens so my way of capturing images is different. I adjust the settings in advance to have as little fish eye as possible, set the frame rate, and film blindly. If underwater, I attach the Go-pro to my head, or hold it in my hand to increase control over its position. I attach the Go-pro to my torso and film when walking in public – particularly on significant journeys: In Porto I filmed the journey from my hotel room, through the streets, onto the underground, and to the hospital entrance where I was to meet a pathologist who specialised in HDGC.

I use my father’s old Pentax film camera to capture still images. I love looking through the lens of this camera (I tried and failed to get an adaptor to use it with my digital camera). I take pleasure in looking and carefully adjusting the focus. I am very still and the world appears very still. The process of my capturing still images is focused and inward looking.

I download all the digital images I capture – still and moving – onto my computer. First I look through the images and delete any of poor quality. I look through my archive of images periodically but do not delete anything. When I come to make work, I look through everything that I have captured to select images for the work – by this stage, I have a sense of what I want to make. Based on this sense, if it is moving image, I put all the footage in which I am interested in a library. I look through the clips, dragging them onto a timeline using Final Cut. I make a first rough cut based on the idea for the work. My initial idea or sense of the work is strong but decisions made in the editing process influence the work. I look at the clips in close detail to determine where to cut each frame until I am happy with how they join together. I look at colour, light, rhythm, and movement – and particularly movement across the frame. I only use the blade tool to cut and join clips – transitions are of no interest to me and I do not modify the images in post-production. Once I complete this first edit, I look again and make adjustments. I leave the edit for some time before looking again to see how it works together as a whole. I make any adjustments and add titles before exporting the work.

Making and Presenting Work

Reflection on possible differences between making work for myself to explore my experience and for others provides an opportunity for conscious self-reflexivity. These possible differences might arise as fieldwork, reflective diary writing, and video sketches – methods I use – are considered, by Bolton and others, as support structures for reflection as opposed to a finished product.[289] Commonly, the output of these methods would be 'worked up', edited, and re-worked until the maker was suitably satisfied with the finished work so that it could be presented to others. With narrative work, this may involve an element of what Newman refers to as 'smoothing over'.[290] In *Performance and the Medical Body,* Emma Brodzinski cites the artist Brian Lobel reflecting on his performance work *BALL*: 'BALL was a survivor story … [it]

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[289] Bolton, *Reflective Practice*, p. 163.

[290] Hayley Newman is interested in subjectivity, documentary, performance, fiction, and the exploration of how collectives and individuals function, University College London, Slade School of Fine Art, *Dr Hayley Newman, Teaching Summary* <http://www.ucl.ac.uk/slade/people/academic/profile/HJENE78#teaching-summary> [accessed 28 June 2107].

attempted to highlight the clichés of "the cancer story" while engaging in every single one'.[291] Fully aware of the conventions of the culturally sanctioned illness story, Lobel experienced discomfort with the material he had left out of *BALL*.[292] Addressing this, Lobel wrote *Other Funny Stories about Cancer* – a 70-minute stage performance that includes previously self-censored material.[293] This example highlights some of the decisions that might be made (and issues considered) when making work for others. I too am aware of the cultural expectation of creating narratives that exemplify the conventional patient narrative structure, with its emphasis on linearity, transformation, closure, and plot. While I desire this type of narrative, my patient experience is different. I find the exploration of these tensions to be generative.

Returning to Bolton's use of the term 'support structures', I make visible the structures that support my works, revealing the construction of my narratives, which entails very little – if any – distinction between making work for myself to explore my experience and for others. See, for example, *Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia,* where the video element of the piece shows its construction through the editing process; *Traces, as Evidence That Conversation Happens* and *Testing*, *Testing: Testing, Memories, and Notes* where fragments of fieldwork notes and diary entries are employed in the final work. My 'finished' works have a raw quality and there is often sense that they are in fact unfinished; that they could be reactivated in the future. For me this is a strategy – which works with the tentative, sensitive, and fragmentary – to intervene with the ubiquitous and culturally expected form of patient narrative.[294] In showing the construction of narratives that do not exhibit the tropes of the patient narrative, I offer these narratives as alternatives, inviting critique and dialogue on their value and formation.

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[291] Brian Lobel, *BALL and Other Funny Stories About Cancer*, London: Oberon Books, 2012, p. 15. Cited in Emma Brodzinski, 'The Patient Performer: Embodied Pathography in Contemporary Productions', in *Performance and the Medical Body,* edited by Alex Mermikides, and Gianna Bouchard, London: Bloomsbury, 2016, p. 91.

[292] Emma Brodzinski, 'The Patient Performer: Embodied Pathography in Contemporary Productions', in *Performance and the Medical Body,* edited by Alex Mermikides, and Gianna Bouchard, London: Bloomsbury, 2016, p. 91.

[293] Emma Brodzinski, 'The Patient Performer: Embodied Pathography in Contemporary Productions', in *Performance and the Medical Body,* edited by Alex Mermikides, and Gianna Bouchard, London: Bloomsbury, 2016, p. 91.

[294] Jo Spence, for example, was driven to make visible spheres of life that remained unseen – the body with cancer or women at work, for example.

Since my position in this research is as artist, researcher, and patient, I face other cultural and institutional expectations, which stand in contrast to the culturally sanctioned patient narrative structure. As funded Ph.D. candidate, unlike professional artists, I do not have to make a living from my art practice and so the external pressures on me are distinct: above all, my work must function as research; within this stricture, I am relatively free to explore my patient experience in my work. However, as research, my making should deliver insights, advancing my research enquiry.

A second way of interpreting possible differences between making work for myself to explore my experience and for others, concerns the instrumentalisation of art to explore experience of genetic illness; the instrumentalisation of experience of genetic medicine for art practice; and the intrinsic value of art. Proper engagement with this wider debate cannot be undertaken here – it is not the focus of my study and moreover, it is largely attended to elsewhere (see, for example, Claire Bishop's book *Artificial hells: participatory art and the politics of spectatorship)*.[295] However, attention must be paid to my own values and actions and their possible effects on others – on individuals and on social, political, cultural, and intuitional structures. Reflecting on my art practice, before my diagnosis I made work that explored narrative and this has continued post-diagnosis. Initially, while personal, often concealed, narratives were the starting points for my works; my work explored escape. During the Ph.D., I focus more on my experience of genetic medicine – exploring and revealing those experiences, which were hitherto concealed.

My making is conducted with an imagined audience in mind; while I document and explore my experience in my art practice as research, I expect that these textual and visual explorations will be presented as patient narratives to art audiences, peers, patients of genetic medicine, and people working in the clinical field of genetics. In so doing, I hope that my work might help others. When a patient of genetic medicine

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295 Claire Bishop, *Artificial hells: participatory art and the politics of spectatorship,* London: Verso Books, 2012.

encounters my work, they might recognise a shared experience, which may then be used as a model for their own communication. When people working in a clinical or academic context encounter my work, they might see in my works alternative narratives of patient experience of genetic medicine, opening up the medical discourse and the patient experience.

Gray and Malins write that seeking the views of others gives what the social and health sciences professor Colin Robson calls the 'practitioner-researcher' recourse to inter-subjective views; while subjective, these are less likely to be biased due to their multiplicity and exteriority.[296]

The goal of objectivity appears to remain influential. Parker writes that rather than adopting a subjective position as a 'merely subjective' position and making claims in opposition to 'facts' discovered through objective study, a subjective position should be a 'self-consciously and deliberately assumed position'.[297] While I do not strive for objectivity, critical comment on my work from others is imperative in guiding the work.

Central to my practice, the presentation of work and my awareness of its reception is a method. I present my work in different contexts to a range of external audiences (including non-academic audiences), to test the work and invite dialogue on the potential application of patient narrative, as informed and told through art practice. (See Appendix Two for a list of exhibitions and presentations.) To date: live performances embedded in lectures, symposiums and conferences, works in gallery exhibitions and book fairs, and texts in books. Exposing my work and soliciting feedback from others is intended to prevent the work becoming too enclosed (given my position in this work as artist, researcher, and patient).

While sharing work that is personal, raw, and largely unedited entails a level of vulnerability, the necessity of so doing (for my work to function as research) trumps

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[296] *Colin* Robson, *Real World Research,* Oxford: Blackwell, 1993, p. 446. Cited in Gray and Malins, *Visualising Research,* p. 23.

[297] Parker, *Qualitative Psychology*, p. 25.

any difficult consequences. In light of this, I often have to force myself to show work to others. I feel this most acutely when performing works; when video work includes nudity; and when I am close to audiences members, who might be my family members or close peers. In my letter *Dear García,* I reflect on the difficulty of writing with multiple different possible audiences in mind. I write:

> I imagine a reader and it silences me. Perhaps I simply want to write and not be read, so that I can write. I'm not sure I can ever really express myself to an other: More troublesome still is that, as part of my Ph.D., this letter may be read by my examiners and so I wonder how I can really write to you.

At the time of writing I wanted to acknowledge the difficulty of writing authentically for multiple audiences – Dora García, my supervisors, my examiners, and anyone who might read my thesis in the future. This serves as an example of where I self-reflexively acknowledge the attention paid to – and attempted disregard for – how my work is experienced by others. This is reminiscent of the dissonance I felt when performing *Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia* at the HDGC Patient Information Day in Cambridge to an audience that included patients, clinicians, researchers, and family members (see discussion on page 121). Relatedly, though not an example of my art practice, my experience of being in hospital post-gastrectomy where I consistently reported that I felt well (despite feeling the contrary), exemplifies a scenario in which I 'performed' positivity, rather than revealing my real feelings (see discussion on page 41). Making authentically is, for me, a challenge of autoethnographic practice.

I have found the most successful method of presentation to be when a spoken discussion was scheduled into the presentation of works; in these instances audience feedback and discussion was most forthcoming. Less successful methods have been the soliciting of feedback in written forms – *via* a letter given to people who bought my work *Untitled 2014;* and on a clipboard with papers stamped confidential, suggesting medical observations accompanying my work in the Design4Health exhibition, 2015. As is expected, formal Ph.D. examination points, supervision meetings, and critiques provided further occasion for me to show work and invite feedback for reflection. In relation to *ST298.402* for example, the distinction between patient experience and genetic patient experience was questioned and some viewers felt that *ST298.402* communicated something of the former only. I considered in what ways I am a patient in its broadest sense, in what manner my status as a patient of genetic medicine might differentiate me, and how, where, and why these experiences overlap. If possible to demarcate my experience as a patient of genetic medicine, I explore how my work might attend primarily to these experiences.

Exploring the Work of Others

I explore the work of others to generate enquiry. In *Sculpting in Time* Tarkovsky writes of a time at the beginning of his career in cinema when he looked to build up a 'repertoire of expressive techniques':[298]

> I was looking for forerunners, for parents, for a single line of tradition that would not be broken by my illiteracy and ignorance. I was simply getting to know cinema in practice: the field in which I was to work.[299]

Given my desire to work in moving image (a medium in which I lack formal training), I look to the work of others to develop my knowledge of the medium, to further understand what I am doing, and to extend my repertoire of methods for exploration. As a patient, artist, and researcher exploring the narration of my patient experience, I make detailed readings of two films by Jean-Luc Godard *Passion* (1982) and *Scénario du film 'Passion'* (1982) and Dora García's film *The Joycean Society* (2013), discovering narrative elements, which inform and expand my production. The work of others provides a framework for my practical experimentation, simultaneously enhancing my understanding of different approaches to narrative, discovering areas to explore through

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[298] Tarkovsky, *Sculpting in Time*, p. 88.
[299] Ibid.

production, and providing models for addressing patient narrative in a meaningful way. My readings follow in the next chapter.

Schön's 'knowing-in-action' is a type of knowledge – knowing how as opposed to knowing what. Knowing-in-action is an intuitive, personal knowledge, not easily articulated and sometimes indescribable. Schön's writes that practitioners' difficulties in articulating this kind of knowledge is responsible for the separation of academic and professional practice. Gray and Malins write that this is the cause of the fears in research in art about the possibility of negating creativity through writing about it.[300] Through exploring the work of others, I am better able to breakdown this mystery of knowing-in-action and articulate my making processes.

I develop methods of looking to elucidate narrative strategies, exploring how this might facilitate my own work. I watch *Passion, Scénario du film 'Passion',* and *The Joycean Society* repeatedly, taking handwritten notes. Sometimes, I watch the films with others but mostly I watch alone. I watch the films on my computer, either at home or in the art studio. With the exception of *The Joycean Society* – which I viewed installed at the Tetley Gallery, Leeds, in February 2017, in García's exhibition *These books were alive, they spoke to me!*[301] – I watch with one hand on the pause button, stopping and rewinding frames and scenes to look and listen in close detail and take notes. In this way, I see differently. I employ techniques similar to those of reading texts: skimming for overall gist and scanning for specific features. Once I isolate something of interest, I look closely and repeatedly, making a detailed reading. I sometimes video myself watching and photograph my watching set-up. The way I watch is no doubt different from how García and Godard intended: *The Joycean Society* is installed in exhibitions (though can be seen online on vimeo with a password), *Scénario du film 'Passion'* was made for television, and *Passion* belongs in the cinema.

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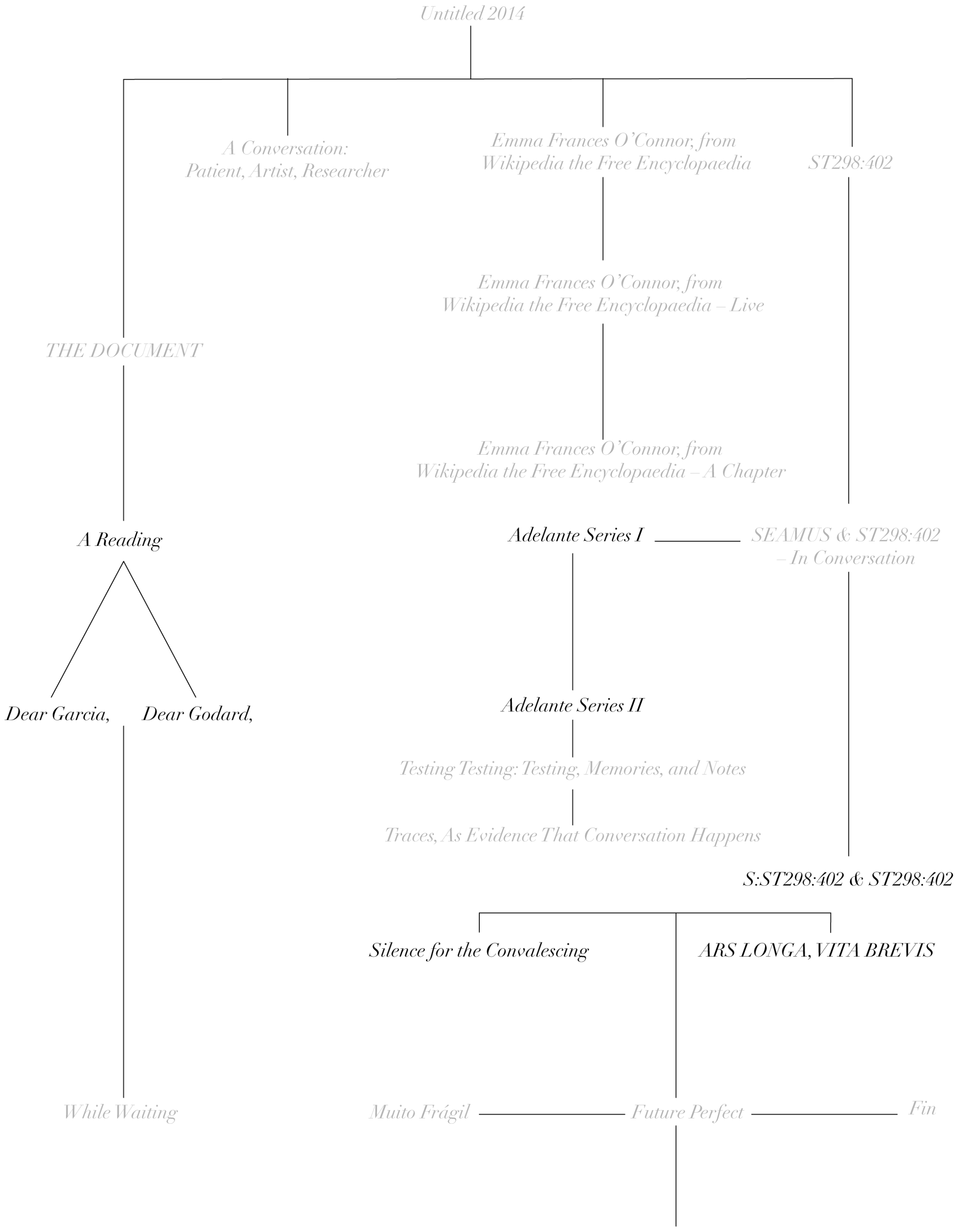
[300] Schön, *The Reflective Practitioner*, p. 308–309. Cited in Gray and Malins, *Visualising Research*, p. 22.

[301] García took the title for her show from François Truffaut's 1966 film *Fahrenheit 451* (an adaptation of Ray Bradbury's novel *Fahrenheit 451* (1953) about a society with no (legal) books). Truffaut's *Fahrenheit 451* is a film about reading, memory, and embodiment – all of which concern me as much as García (themes and connections echoed in my work *Dear García,)*.

I develop different ways of looking in response to the different works. I watch *The Joycean Society* repeatedly in its entirety. My writing reflects this as I think about the circularity in the way that the readers read Joyce; how with each reading, they discover or construct new meanings. This brings an interesting dimension to my looking, one to which Stone attends in *Running Man,* and one that surely surfaces in a research project spanning a number of years: each time I re-view a work, I look with new eyes. In the interim between watching, all the quotidian and more remarkable occurrences of life come to pass – experiences that change and inflect my looking, what I see in the works, and how I interpret this. Replaying the same sequence is often not the same and this openness to an exploration of multiple readings and possibilities enhances the work and my enjoyment of the process. Later, I read critical texts on the films, drawing together the work of others, my making, and theory. The writing of others develops my vocabulary for reading film and my understanding of the processes at work in my own art practice.

PÉ DE GRUE —— PEDIGREE III



PÉ DE GRUE ———— PEDIGREE III

A Reading — Dear Godard, — Dear García, —
Adelante Series I — Adelante Series II — S:ST298:402 & ST298:402 —
Silence for the Convalescing — ARS LONGA, VITA BREVIS

A Reading

A Reading was developed using a transcription software programme to transcribe a conversation between a geneticist and me. Our fleeting work together began with a chance meeting in the sauna of my local swimming pool. He was Italian and I offered to help him with his English; in exchange he would help me to understand something of the science of genetic mutations. We talked about genetic mutations – how sometimes they have meaning – affecting change – and at other times, they do not (where is the causality here? No one knows). The transcribed conversation was so distorted it made little sense. I read it with my father to an audience. It was strange directing him, reminding me of how in *Scénario du film 'Passion'* Godard describes working with actors in *Passion* – he speaks of resistance from crew and cast members to his way of working and scripting; cinema, says Godard, is an industry-driven art form with conventions that are difficult to bypass. Yet, by remaining in the cinema, these generative tensions remain and are productive.[302] My father was anxious about what I wanted him to do, which was simply to read, together. The text is continuous with no division or indication of two separate reading parts. He wanted to know where he would start and end and where and when I would begin. I wanted to just read it and see what happened. Despite my refusing a rehearsal, when we read, we divided the text spontaneously and fluently. It became a type of communication, meaningless yet with much meaning.

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302 I feel similarly about the conventions of a Ph.D.; while exploring the boundaries of conventional patient narratives, I am cognisant that I am also working within the strictures of academia and the structural form of a Ph.D. thesis.

Godard's use of noise to obscure and simultaneously communicate reminded me of genetic mutations. When we read for an audience, I think about the role of the narratee and their tolerance for what I understand is received as noise.

Watching *The Joycean Society* I thought more about communal reading, its relation to meaning making and healing. The transcript – a difficult text – enabled the exploration of multiple meanings. I was thinking about genetic scripts and genetic diagnoses in a similar way – my father also has the HDGC genetic mutation and has had a prophylactic gastrectomy. I thought about patient narrative, my fluctuating health as one of uncertainty, and whether illness must be made meaningful to be endured.

Dear Godard,

In *Jean-Luc Godard par Jean-Luc Godard*, Godard writes about a proposal he made to the *Centre national de la récherche scientifique* (CNRS) suggesting that cinema be used to '*résoudre une fois toutes les questions du cancer*' ('resolve once and for all the problems of cancer').[303] The CNRS did not reply. *Dear Godard,* is an epistolary work – a letter to Godard – outlining my proposal (which builds on how I imagine Godard's proposal) for how we might explore my experience of genetics with cinema. I enclose my maquette *Future Perfect* in my letter to Godard.

Dear García,

Dear García, is an epistolary work – a letter to Dora García. I recount a tale about communal reading and a search for meaning, exploring ideas about acting, reading, memory, embodiment, and translation, at the same time drawing connections with *Fahrenheit 451*. Prompted to write the letter by another, I consider how I can account for myself through different modes of address.

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[303] Jean-Luc Godard, *Jean-Luc Godard par Jean-Luc Godard, Tome 1: 1950-1984,* Paris: Cahiers du Cinéma, 1998, p. 463. Cited in Morrey, *Jean-Luc Godard,* p. 158.

Adelante Series I

Adelante Series I is a 1-minute 40-second video work. Much of the footage, filmed on my mobile phone in portrait, is of my feet walking to hospital appointments. This was secret filming, as I did not have permission to film in hospital – I was thinking about where one can and cannot film in daily life and as a researcher. The lines on the floor (broken, institutional lines) make me think about multiple possible narratives – about destiny, choice of narrative, and about how narratives might be co-constructed by patients and doctors. The hospital walking footage contrasts with footage taken on my digital SLR camera in landscape format, in which I am also walking, but through the Alcázar of Sevilla. In these shots, there is no synchronised sound, which in my view creates a feeling of disembodiment. Non-synchronised sound of the opening of electric hospital doors punctuates the shots. I was also thinking about movement, particularly stepping in relation to agency and momentum – placing one foot after another.

Adelante Series II

Adelante Series II (2016) is a window projection – looped video; blue, red, green, yellow, and orange adhesive floor marking tape – 50 mm wide; queue management system display, radio control, and ticket dispenser. I developed the work while thinking about place in *Passion,* which brought to my attention the places that are marked for me as a patient – home, hospital, waiting rooms, doctors' rooms, hospital wards, theatres, toilets. I thought about how I traverse between these spaces. Emotionally, moving between these spaces is almost always extreme and in flux. This manifests in bodily movement, expression, and my voice. I was thinking about Godard's use of pace, and rhythm, and movement, about *being in* the world and the everyday as opposed to the heroic. I was cognizant of Pierre Bourdieu's concept of *habitus* – reflecting on my experiences of moving between significant places (and the changes in my movement through these spaces) with this lens. Reflections on the crit that followed exhibition of *Adelante Series II* (in my text *Traces, as Evidence That Conversation Happens*) relate also to Bourdieu's *habitus,* illuminating social, cultural, and institutional dispositions to speak in certain ways. My use of institutional languages situates *Adelante Series II* as a commentary and critique on the embodied relations of power and privilege in institutional settings.

The narratives I employ in *Adelante Series II* are disruptive in so far as they, like a genetic diagnosis, promise and deny direction. While viewers may take a ticket from the dispenser and wait for their number to appear, it is not clear what, if anything, will happen; the coloured lines on the floor appear to offer direction, yet seem to lead nowhere.

S:ST298:402 & ST298:402

Reading theoretical texts about montage, I found a new way to think about my use of montage in *ST298:402* as a way to begin to dismantle the binary of illness and health – as I am living it, not as my quest but as my everyday *being in the world*.

I understand montage in *ST298:402* as a way to explore and articulate the third, indeterminate space I find myself occupying, between illness and health: my *living in* prognosis, my *being with* risk. I was thinking not only about travelling between the two – illness and health – but being in-between the two categories, which at once seemed more fluid.

Watching *Passion,* I became more aware of the potential of sound and this developed my understanding of how the use of layered non-synch sound might function in *ST298:402*. In a particular one-minute section of the video, sound and images from the *Semana Santa* parade in Mallorca are layered with images of a swan and the dark interior of a hotel room. The sound – a walking brass band and drums from the *Semana Santa* procession – has, for me, a strong emotional content, and together with the images builds to a climax. In *My Last Breath,* Luis Buñuel dedicates a chapter to 'The Drums of Calanda', a ritual he finds powerful and strangely moving. Buñuel writes of the ancient Calanda Easter ceremony, which dates back to the end of the eighteenth century. The drums are beaten from noon on Good Friday until noon on Saturday. One day Buñuel decided to surprise friends with a serenade; they too found it powerful, although they were unable to say why. Buñuel – who has used this rhythm in several of his films, especially *L'Age d'or* and *Nazarin*,[304] writes that the sound seems to 'echo some secret rhythm in the outside world, and provokes a real shiver that defines the rational mind'.[305] I am drawn to the rhythm in much the same way and it is a sound. This reminds me of Nancy Huston's novel *Danse noir,* which, in part, takes on the rhythm of Brasilian capoeira.[306]

S:ST298:402 is a short book and a film poster – an accompaniment to *ST298:402 –,* forming part of *The Editions* project*,* stewarded and edited by Dr Sharon Kivland.[307] The book was intended as a thread, albeit a fragile thread, that might function to sew those images (in *ST298.402*) together. I tried to write a story. And then – because I was not sure that I could do it – I asked others to: In *S:ST298:402,* two pieces are included; one written by my father, the other by my mother. These pieces sit beside other fragments: a photograph of Mod, a quote from Carlos Fuentes about memory, a book dedication in Jorge Luis Borges' *Ficciones,* barely visible hospital letters, email exchanges, sections of screenplay, patient diary entries, a postmark from Portugal, a figure of an example gastrectomy specimen processed for pathology, a city map of Lisbon, and a sound script for *ST298.402*. The making of *S:ST298:402* was a pleasurable and satisfying process and I reflected on this in the afterword. The book format facilitated my exploration of elements – fragments – of my patient experience and indeed my self, which when presented together in the book narrated my story in a gentle manner. As a back story to *ST298:402,* I was thinking about what is 'off-screen' and what is 'off stage'. The poster – a black and white image of an airport waiting area with planes and my reflection just about visible – is a speculative film poster. The image fills the page and overlaid text reads '*A poster for a film, ST298:402, by Emma*

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[304] Luis Buñuel, *My Last Breath*, translated by Abigail Israel, London: Vintage, 1994, p. 20 [*Mon Dernier Soupir,* Paris: Editions Robert Laffont, 1982].

[305] Ibid.

[306] Nancy Huston, *Black Dance,* New York, NY: Black Cat, 2014 [*Danse noir,* Paris: Editions Actes Sud, 2013]

[307] *S:ST298:402* was exhibited as part of *The Editions,* a limited edition collection of artists' books and posters – at Leeds Artist Book Fair 2015, the Hepworth Print Fair, The Floating Library (Silverwood Park, Minneapolis), and Liverpool Artists' Book Fair 2015. The edition is in the collection of Tate Gallery, Tate Library and Archive.

O'Connor'. I thought about why Godard made *Scénario du film 'Passion'*, wondering if his motivation bore any relation to mine – an attempt to fix narrative.

Silence for the Convalescing

In my moving image work *Silence for the Convalescing* (2'42'') I edit video footage of my hospital X-rays together with moving images taken on a train journey of clouds and smoke, as well as a reflection of a Moorish Palace in rippling water. The black and white x-rays function as filmic disruption – their materiality interrupting the dreamlike footage of clouds taken from a train window. The x-ray footage is topographical, further suggesting landscape and connecting to the little journeys of my quest.

I was thinking about *Passion* and Benjamin's question of how the cameraman compares with the painter.[308] I read that Godard says that *Passion* exists somewhere between the stomach and the lungs. With the inclusion of X-ray footage, I was exploring ways of capturing and looking, thinking about how the hospital cameras look through the surface of my body to new surfaces. I thought about how surface might be preserved, distorted, transgressed, seen through, and created with technology.

ARS LONGA, VITA BREVIS

In *Ars Longa Vita Brevis* (5'29'') – a moving image work – I video myself fleetingly in reflective surfaces and in images. I was thinking about how Godard employs staging and framing as ways to explore and analyse what it is to be a patient of genetics, with the stage conceived as a potential critique of a genetic patient's exploration of her/his position and status as patient. Employing film techniques to explore 'off-screen/offstage' relations in the creation of a genetic patient narrative to explore how I might reveal and obscure myself: a play of showing, hiding, looking at and looking

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[308] Walter Benjamin, 'The Work of Art in the Ages of Mechanical Reproduction', in *Illuminations*, London: Pimlico, 1999, p. 226. Cited in Anna Manubens, 'Godard's Lingering Camera From *Le Mépris* to *Passion* and Back', *Critical Quarterly,* 53, 2011, 208–24 (Issue Supplement: *Godard's Contempt, Essays from the London Consortium,* edited by Colin MacCabe and Laura Mulvey) p. 212.

through. The ‘off-screen/offstage’ relation helps me see how my work generates knowledge: How I reveal and obscure myself (my self) through the reflections is the problem of patient narrative in miniature.

At the end, I video myself quite differently in the mirror of a hospital changing room cupboard. I’m dressing after an MRI scan. It was a traumatic experience and my body is marked and blotchy. This last scene marks a departure from my previous work as I figure in it, not fleetingly but blatantly and uncomfortably as a patient. The Return of the Patient. Something that had previously been missing as I realise much of my art practice before my Ph.D. had functioned as a means of escape. The inclusion of me as patient sets up and dismantles the apparent binary of patient and healthy person.

Desire Lines: Looking Afar and Anew, Expanding my Narrative Resources

Introduction — *Passion,* directed by Jean-Luc Godard — *Scénario du film 'Passion',* directed by Jean-Luc Godard — *The Joycean Society,* directed by Dora García

Introduction

Recalling Frank's observation of a common stock of narrative resources for the representation of experience,[309] and Waddington and Willis' claim that the paucity of methods used to explore patient narrative restricts their meaning and forms,[310] I look to the work of others for new ways to explore my experience of genetic medicine, expanding the array of narrative resources available to articulate my experiences.

In turning away from self-help books and online communities for patients, which demonstrate more predictable narrative structures, I consider what is to be found in unexpected places, bringing something new and different into the context of patient narrative. I choose not to conduct close readings of the more obvious precursors to this work – works by artists including Jo Spence, Lynn Hershman-Leeson, Steve Dwoskin, and Derek Jarman, to name a few examples (see pages 4–11). While *Re-imagining Patient Narrative* could not exist without these artists, insights from their works and processes have been previously considered in a medical context and moreover, these artists do not address experiences of genetic medicine, which are distinct from illness, presenting different challenges to narration.

Instead, I make detailed readings of Godard's *Passion* and *Scénario du film 'Passion',* and García's *The Joycean Society* – each selected for its potential to challenge patient narrative. Focusing on their narrative processes and though an engagement with theory, I search for narrative elements to inform and expand my production. Choosing only

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[309] Frank, 'Practicing Dialogical Narrative Analysis', p. 40.

[310] Keir Waddington and Martin Willis, 'Introduction: Rethinking Illness Narratives', *Journal of Literature and Science*, 6, 1, 2013, iv–v <http://www.literatureandscience.org/wp-content/uploads/2013/09/JLS-6.1-Complete-Issue.pdf> [accessed 28 June 2107].

three works enables me to develop a close looking that would not have been possible had I considered a greater number of works. In limiting my detailed readings, I demonstrate that my selections are not exhaustive or comprehensive, opening up possibilities for further looking and learning.

While the following reflection on the time of my first encountering *Passion, Scénario du film 'Passion'*, and *The Joycean Society* illuminates the initial rationale for their selection, the full justification for their place in this study only fully emerges with the consideration of detailed examples of where and how they offer specific insights for this research enquiry, creative practice, and thinking about narrative form and function. This is discussed further in the remainder of this chapter, and the concluding chapter *Patient Narrative Re-imagined*.

My decision to look closely at *Passion, Scénario du film 'Passion'*, and *The Joycean Society* may be traced to 1 October 2013 – the first day of my Ph.D. I was recovering from sub-acute bowel obstruction, a complication that can arise after abdominal surgery due to adhesions (scar tissue adhering to further scar tissue in the bowel area). I settled on the sofa and watched *Passion*. My initial reasoning to look more closely at *Passion* proceeded according to a particular type of reasoning, like Joan Didion's magical thinking referred to in the title of her book *The Year of Magical Thinking*. This magical reasoning is a primitive instinct – Didion's need to be alone so that her husband might come back, for example. It is an anthropological magical thinking with the fallacious implication of causal relations. A hard-to-shake-off magical reasoning placed importance on *Passion's* 'day one' position in my Ph.D. lifecycle.[311]

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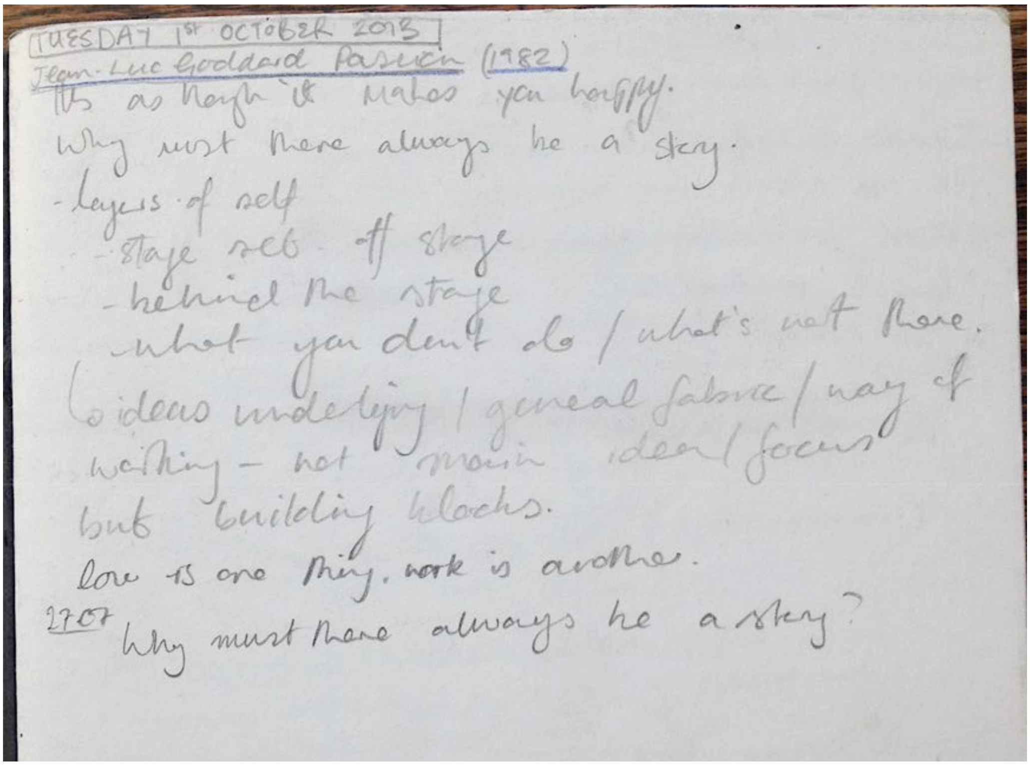
[311] This magical reasoning was not new to me: Before receiving the results of my genetic test, I remember being by a river in the Derbyshire countryside, making a pact with myself that if I swam in the freezing water, the results of the test would not show a genetic mutation. As it happened, I soon learnt that there was no causal relation between my freezing in a Derbyshire river and the results of my genetic test; I consciously attempted to banish this type of thinking. This was fortunate because in hospital on the night before surgery, I had a small ceramic angel figurine by my bedside (clearly I was holding on to some of my magical reasoning) and the nurse knocked it and its head fell off.

Figure 2



TUESDAY 1st OCTOBER 2013

Jean-Luc Goddard Passion (1982)

Its as though it makes you happy.

Why must there always be a story.

- layers of self
  - stage set - off stage
  - behind the stage
  - what you don't do / what's not there.

↳ ideas underlying / general fabric / way of working – not main idea / focus but building blocks.

love is one thing. work is another.

2707 Why must there always be a story?

Ph.D. diary entry – 1 October 2013

Variations of the question *Qu'est-ce que c'est que cette histoire?* (What's the story?) recur frequently in *Passion*'s dialogue: in the opening scenes, and in the first five minutes, it is asked three times.[312] This persistent line of questioning becomes increasingly frustrating for filmmaker Jerzy who, exasperated, questions why there has to be a story. In my recovery and thinking about patient narrative, I too questioned why there has to be a story and so my relation to the film was both strong and personal. At times, I feel that the question driving my research enquiry is indeed whether and why there has to be a story. I see Jerzy's searching as a quest, which in many ways – and like my own – is a failed quest.

The title *Passion* is also significant. As I embarked on my first journey to Portugal for a conference and in search of my stomach, I wrote a diary entry about searching for my

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[312] This might also be understood to mean 'What's going on here?' See: Maria F. Marquez, 'Art and Women as Thresholds of the Sublime: The Gendered Limits of "the method of BETWEEN" in Godard's *Passion*', *Australian Journal of French Studies*, 49, 1, 2012, 18–30, p. 22.

stomach and searching for passion. I write about seeing passion in the gardens of the Guggenheim Museum in Lisbon, and about looking in a hotel mirror and thinking that I see it in myself – that I could feel it – but felt silly trying to film it. Later, I read a quotation from Godard: *Passion* is a film that takes place 'quelque part entre l'estomac et les poumons'.[313]

Passion led me to *Scénario du film 'Passion'* – a self-reflexive work, where Godard reflects on his methods of scripting *Passion*. Given my interest in the construction of narrative, this seemed auspicious and gave momentum to my readings.

I was then introduced to Dora García's *The Joycean Society,* by Dr Sharon Kivland my Director of Studies. I was instantly taken with the film – the reading, the idea of the quest in relation to the work, and its connection to the literary –, watching it propelled me onwards, stoking my enthusiasm for my work. My interest deepened with each viewing as I saw multiple possibilities for new understanding.

It is also pertinent to acknowledge my need – as a patient – to look away from illness. While secondary to considerations more directly related to my research enquiry, my choice of case studies was also motivated by a need to sustain momentum over a four-year research project. Immersion in illness – my own experiences and the narratives of others – can at times feel overwhelming. Thus, the case studies offer me a period of respite and reinvigoration, which rather than compromising my enquiry, is extremely productive.

The words 'Desire Lines' in the title of this chapter encapsulate the strength of my desire – albeit unexpected – to turn to these three works for a period of autodidactic, independent, self-directed, and highly self-motivated learning.

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313 ('Somewhere between the stomach and the lungs') Jean-Luc Godard, *Jean-Luc Godard par Jean-Luc Godard, Tome 1: 1950-1984,* Paris: Cahiers du Cinéma, 1998, p. 484. Cited in Douglas Morrey, *Jean-Luc Godard*, Manchester: Manchester University Press, 2005, p. 153.

Passion, directed by Jean-Luc Godard[314]

'Qu'est-ce que c'est que cette histoire 'Mademoiselle' Lucachevsky?' — 'Qu'est-ce que c'est que cette histoire Monsieur Bonnel? — 'Qu'est-ce que c'est que cette histoire Monsieur Courtard?'

I take the first three occurrences of the question *Qu'est-ce que c'est que cette histoire?* in *Passion* to discuss Godard's development of narrative, exploring how, in place of a conventional linear narrative, meaning is made and finds form.

'Qu'est-ce que c'est que cette histoire 'Mademoiselle' Lucachevsky?'[315]

Passion's opening sequence begins with a shot of a blue sky with a few white and grey clouds filling the frame and Maurice Ravel's *Piano Concerto for the Left Hand in D major*. The camera, which appears to be hand-held as its movements are not fluid, captures the vapour trail of an aeroplane piercing the clouds as its moves upwards and away from earth. After approximately forty-five seconds, there is a cut to the factory – to factory worker Isabelle (Isabelle Huppert) pushing three stacked metal boxes on wheels. To the left of the frame is factory machinery and equipment. For the short duration of the shot (c. nine seconds), Isabelle advances along the right of the frame towards the camera. When she reaches the centre of the frame, there is a cut back to the blue sky (minus the plane – is the camera searching for it?). The shot lasts just under ten seconds as the camera moves unsteadily up, to the right, and then down, reminding me of a kaleidoscope. There is a cut to Jerzy driving a car. The driver's window is wide open and Isabelle, cycling alongside, holds onto its frame with her right hand. In the background is the blue sky with dispersed vapour trails. Isabelle and Jerzy look forwards in their direction of travel. Isabelle, occupying the right third of the frame, looks down to Jerzy, whose face moves into profile as he meets Isabelle's gaze. Their

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[314] *Passion*, dir. by Jean-Luc Godard, Parafrance Films, 1981.

[315] 'Mademoiselle' is placed in single quotation marks to reflect the language used in *Passion* while also taking some critical distance from this use, no longer deemed acceptable and now removed from official forms after feminist organisations campaigned against its differentiation of women by marital and civil status.

sight line is paralleled with the diagonal shape created by Isabelle's arm on the doorframe. They look away from each other. This travelling scene lasts less than five seconds: Jerzy looks back at Isabelle and there is a cut to the blue sky, which with its grey and white clouds fills the frame. The camera moves jerkily upwards and the vapour trail becomes visible – the plane flies up and diagonally to the left. The shot lasts for approximately thirty seconds before there is a cut to the hotel. Hotel owner Hanna (Hanna Schygulla) occupies the centre third of the frame as she dresses. The pink of Hanna's shirt matches the bathroom tiles in the background. Michel, the factory boss (Michel Piccoli), walks into the bathroom. After about six seconds, there is a cut back to the same blue sky – the vapour trail splitting the frame diagonally in two. The camera angle is lower, capturing treetops in the bottom left of the frame. The camera pans jerkily from right to left. There is an absence of diegetic sound throughout this entire sequence. The music, which has been continuous throughout, climaxes. There is a visual cut and diegetic sound simultaneously enters the soundscape.

A long shot of a driveway, with a wide angle, captures wild grasses and plants in the foreground; in the middle ground there is a tree with few leaves, a parked film lorry, a wooden building, and track-like road; in the background there is a field, buildings, hills, and blue sky – all pastel colour. The music stops. The camera is fixed while a frenzy of staccato movement takes place in the centre of the frame as characters come and go in cars with horns blasting. The leaves and tall grasses framing the action make tiny shimmering movements as they catch the breeze – like the jittering figures in this instant – while remaining stationary, rooted firmly to the ground. After about one minute, there is a cut to Isabelle working in the factory. She is in the centre of the frame, surrounded by large factory machinery, making a lot of noise.

In this opening sequence, Godard establishes three significant marked locations – hotel, factory, and film studio. Unlike much of the action, which occurs between these primary locations – in car parks, outside buildings, on roads, at petrol stations – this next scene takes place in the elaborate theatrical film studio, where Jerzy is directing his film, *Passion*.

An off-screen male voice asks ‘What’s the story, ‘Mademoiselle’ Lucachevsky?’ Simultaneously, a long shot of Jerzy’s film studio reveals thirteen figures dressed in colourful decorative costumes with props of rifles and flags. The spotlit figures take their positions as live actors re-enacting Rembrandt’s 1642 oil painting *The Night Watch*.[316] This is the first of several *tableaux vivants* featured in *Passion* on which Jerzy’s film is based.

The actors’ assembling is accompanied by the diegetic sound of workers in the film studio moving, speaking, whistling, and coughing. As the actors become still in their enactment, the surface of the image flattens. A woman’s voice, that of ‘Mlle’ Lucachevsky (Sophie Lucachevski) the assistant director, responds: ‘It’s not a lie, but something made up, which is never exactly the truth, nor is it the opposite, but which, in any case, is separated from the real world by profoundly calculated approximations […]’. The distance between the diegetic sound and the voice of ‘Mlle’ Lucachevsky causes me to view her position with uncertainty: She seems to be part of the storyworld yet the distance from the rest of the soundtrack suggests a voice-over. The gentle intonation of ‘Mlle’ Lucachevsky’s voice offers a soothing commentary on the film’s action for contemplation – a recurrent strategy of Godard’s.

Suggesting simultaneity, there is a cut to a medium close-up of Isabelle working in the factory – a relatively ordinary everyday factory. Framed with factory machinery, she holds a pen-like metal tool in her right hand. Yawning, Isabelle touches her lips with the back of her left hand. An out-of-focus figure illuminated by soft daylight stands in the background. Contrasting with the previous *Night Watch* scene, the factory is lit with natural light.

While the transition from the film studio to the factory is visually jarring, ‘Mlle’ Lucachevsky’s voice lends continuity as she completes her reply: ‘[…] or verisimilitude’. Slow, emotive, non-diegetic piano music enters the soundscape. The

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[316] Peter Harcourt writes that the paintings re-enacted are all narrative paintings telling stories. Peter Harcourt, ‘Calculated Approximations of Probabilities: Rhetorical Strategies in the late films of Jean-Luc Godard’, *CineAction*, 48, 1999, 8–17, p. 13.

meandering notes of the piano accompany, even nullify, Isabelle's staccato gestures of work. Diegetic sounds of factory machinery are notable in their absence. Isabelle brings the back of her hand to her mouth as she yawns, closing, or rounding off, the shot as it began. Nothing reveals whether she yawns through tiredness or boredom.

In-between

Godard's choice of dialogue for 'Mlle' Lucachevsky's reply establishes oppositions and the relations between them ('the story is not a lie, but something made up'; 'never exactly the truth nor is it the opposite').[317] 'Mlle' Lucachevsky's words exemplify Godard's use of dialogue to explore distinct concepts and what lies between them; an exploratory method, it allows for the blurring, shifting, and re-making of boundaries as opposed to the accepting of predetermined or unexplored definitions and distinctions. Godard also uses this method in his treatment of work and love with dialogue: 'Love is work at a different speed', 'Love is one thing, work is another', and 'We have to work to love or love to work'. Film theorist and professor Ewa Mazierska writes that Godard blurs the division between work and non-work activities, the purposes of which, she writes, is probably to edify work.[318] However, Mazierska writes that since examples of similarity between work and love do not feature in *Passion*, any similarity between them is not reinforced.[319] She concludes that, to the contrary, *Passion* establishes work and love as distinct domains.[320] She questions why Godard employs such aphorisms, regarded by Stuart Hall as empty, since there is no concrete exemplification of their truths.[321] Film theorist and art historian Kaja Silverman writes that *Passion* compels the viewer to rethink relations between concepts traditionally opposed to one another.[322]

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[317] With 'Mlle' Lucachevsky's conjuring a 'true fiction', I recall Jurecic's writing about patient narratives as imperfect but necessary fictions.

[318] Mazierska, 'Searching for alternatives', p. 218.

[319] Ibid.

[320] Ibid.

[321] Stuart Hall, 'European Cinema on the Verge of a Nervous Breakdown', in *Screening Europe,* edited by Duncan Petrie, London: British Film Institute, 1992, pp. 45–53. Cited in Mazierska, 'Searching for alternatives', p. 218.

[322] Kaja Silverman and Harun Farocki, *Speaking about Godard,* New York: New York University Press, 1998, p. 171.

Godard has defined cinema as '*ce qu'il y a* entre *les choses'* (that which is between things).[323] Godard's aim in *Passion,* writes Silverman, is to disassemble opposites.[324] Yet, it is also an *exploration* of opposites, not only their disassembling: Godard proposes dyads to establish difference before dismantling this difference with similarity – as film theorist and professor Peter Harcourt writes; 'confronting contradiction yet suggesting resemblance'.[325]

While Godard articulates relationality in *Passion* through dialogue, he employs other processes to similar effect: *Passion's* opening sequence, despite its longer shots, demonstrates Godard use of montage with its sudden intercutting of the blue sky and fragmentary shots. In *Cinema 2: The Time-Image,* the philosopher Gilles Deleuze refers to Godard's method as the 'method of BETWEEN' – 'between two actions, between two affections, between two perceptions, between two visual images, between two sound images, between the sound and the visual [...]'.[326] The conjunction 'and', as opposed to 'then' or 'either/or', is emphasised in this process.[327] Sequences in *Passion,* seem accumulatory, and do not possess the amnesiac qualities of works that prioritise the conjunction 'then'. This method of construction – an operation of differentiation rather than association – produces a new third potential, making 'the indiscernible, that is the frontier, visible (*Six fois deux*)'.[328] This third space – Deleuze's frontier – is a consequence of the interaction of two images, belonging to 'neither one nor the other'.[329] This shift from the association or attraction of images to the interstice between two images creates 'a spacing which means that each image is plucked from the void and falls back into it'.[330] I understand Deleuze to mean that each image, instead of

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[323] Jean-Luc Godard, *Godard par Jean-Luc Godard,* p. 580. Cited in Morrey, *Jean-Luc Godard,* p. 158.

[324] Kaja Silverman and Harun Farocki, *Speaking about Godard,* New York: New York University Press, 1998, p. 172. Cited in Maria F. Marquez, 'Art and Women as Thresholds of the Sublime: The Gendered Limits of "the method of BETWEEN" in Godard's *Passion', Australian Journal of French Studies,* 49, 1, 2012, 18–30, p. 21.

[325] Harcourt, 'Calculated Approximations of Probabilities', p. 14.

[326] Gilles Deleuze, *Cinema 2, The Time-Image,* translated by Hugh Tomlinson and Robert Galeta, London: The Athlone Press, 1989, p. 180 [*Cinema 2, L'Image-Temps,* Paris: Les Éditions de Minuit, 1985].

[327] Marquez, 'Art and Women as Thresholds of the Sublime', p. 20.

[328] Deleuze, *Cinema 2,* p. 180.

[329] Deleuze, *Cinema 2,* p. 181.

[330] Deleuze, *Cinema 2,* p. 179.

relating the image to what lies outside the frame, each image comes from the interstice (or the cut), and that it is here, to which each image is then released. Marquez writes that montage can only function in this way if relations between images are not imposed by a predetermined plotline.[331] Contrary to classical cinema, where cuts form the continuous, the cut does not form part of that which it separates.[332] In *Passion*, the cut is an interstice that does not belong to the end of what precedes it nor to the beginning of what is to follow; the interaction of two images engenders or traces a frontier, which belongs to neither one nor the other'.[333] At this frontier, there is 'no story'.

Godard's persistent use of montage in *Passion* suggests its generative power. Marquez writes that to remain productive, Godard believes that a state of perpetual 'being in between' must be maintained and not resolved.[334]

Marquez writes that Godard uses this method – of bringing opposing elements together – as a possible means to understand what it is to be human.[335] She refers to a scene in which Jerzy speaks to Laszlo (Lázló Szabó), the producer of Jerzy's *Passion*, about a lighting problem. Jerzy switches off the lights, saying that he sees night and day at the same time, before drawing an analogy with his relationship with Hanna and Isabelle – he is between the two, a situation that they agree is common to everyone. Marquez cites Silverman, who employs 'betweeness' metaphorically to conceptualise linguistic exchange:

> 'Betweenness' now means something like 'the interval' between antagonistic terms. Everyone occupies this position; to be human is to reside within the interval. That does not mean to mediate between contraries until they can no longer be distinguished from one another […] Each one of us has the capacity to journey back and forth every day between the celestial and the terrestrial, the

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[331] Marquez, 'Art and Women as Thresholds of the Sublime', p. 20.

[332] Deleuze, *Cinema 2*, p. 181.

[333] Ibid.

[334] Marquez, 'Art and Women as Thresholds of the Sublime', p. 24.

[335] Ibid.

> sublime and the quotidian, or fiction and documentary, which are placed in a relation of mutual derivation and consequence. Because we are ‘between’, transferal is possible.[336]

Reading Silverman’s use of the inbetween to describe what it is to be human – an occupation or residency within the interval, I find myself objecting to the assumption that for ‘each one of us’ there is the ‘capacity’ to move freely. I cannot help but transpose her ideas to the relation between illness and health and while acknowledging that such a shift in context need not be accommodated, I find the emphasis on the capacity for movement – the concept of an agentic patient – problematic, specifically in the context of genetic medicine.

‘Qu’est-ce que c’est que cette histoire Monsieur Bonnel?’

The same off-screen male voice asks: ‘What’s the story, Monsieur Bonnel?’ Mid-way through his questioning, the scene cuts from the factory to the film studio. Slow, sparse piano music in a minor key continues seamlessly, adding fluidity to the transition. A static camera captures an actor from *The Night Watch* in medium close-up. The actor wears a decorative textured red costume. His face is illuminated as he looks to his right towards the unseen light source; he holds a gun in his right arm, which casts a shadow on his chest and chin. In the background and to his right are two actors, their faces lit warmly yet out of focus. The stationary figures make tiny movements, which vie for my attention.

M. Bonnel (Patrick Bonnel), the cinematographer, responds: ‘It’s because this composition is full of holes and badly filled spaces. Don’t scrutinise the structure, or the shots. Do like Rembrandt, look closely at the human beings, for a long time [...].’[337] Following M. Bonnel’s command, I look closely at the actor’s face, which is in sharp

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[336] Silverman and Farocki, *Speaking about Godard,* pp.188–89. Cited in Marquez, ‘Art and Women as Thresholds of the Sublime’, p. 24.

[337] As with the voice assigned to ‘Mlle’ Lucachevsky, the presence of M. Bonnel’s name in the questioning implies that this off-screen voice is his.

focus. His expression is hard to fathom; as he stares into the distance and into the light, he seems to be somewhere else, lost in thought. The combination of the expression I read on his face, the music, and the intonation of his voice create a melancholic tone.

As M. Bonnel says '[…] and into the eyes', the camera cuts to the factory to a close-up of Isabelle in profile. The piano music is replaced by loud machinery noise. Isabelle turns away from the camera, concealing her eyes and lips from the viewer, and says: 'Lord, why hast Thou forsaken me?' Isabelle continues working until the action (of going down and then up) of the machine she is working on punctuates the phrase with a full stop.[338]

Character

Under the direction of M. Bonnel, I look closely at the human beings in *Passion,* and there are many: three main characters – Jerzy, Hanna, and Isabelle – secondary characters, and extras. Watching Hanna in close-up on a small monitor, Jerzy is told again that the producers need a story. Jerzy replies 'she is a story'. In François Truffaut's film of *Fahrenheit 451* – characters embody books. The characters in *Passion* are stories to be read. In a related way, Harcourt writes that Godard's characters are events, telling their own stories.[339]

Yet *Passion's* characters, like some books, are not easily read. A proliferation of noise in *Passion* – visual noise as branches restrict the camera's view of characters; and auditory noise from goat bells, car horns and engines, factory machinery, aeroplanes, telephones, pinball machines, and tractors – disrupt and destabilise their reading. Douglas Morrey, writer and lecturer in French Cinema, writes of Godard's refusal to fix his characters and films as stable and memorable.[340] Morrey relates this to Godard's

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338 Ewa Mazierska writes that abstraction is an important feature of factory – the factory is nameless and the viewer does not learn what is produced. Ewa Mazierska, 'Searching for alternatives: The evolution of the motif of work in Jean-Luc Godard's cinema in the years 1972-1982', *Studies in European Cinema*, 7,3, 2010, 209–220, p. 217.

339 Harcourt, 'Calculated Approximations of Probabilities' p. 16.

340 Morrey, *Jean-Luc Godard*, p. 152.

understanding of his own identity, which he comprehends in terms of in-betweenness, refusing a stable, individual, and complete identity.[341]

Sound-image dislocation, while retaining a sense of shared community, makes it sometimes impossible to attribute dialogue to individual characters. I first reacted to this as noise, attempting circumnavigation to understand what was happening before relinquishing the need to attribute dialogue to individual characters. Referring to the theoretical biologist Henri Atlan's use of information theory of the organisation of life (that noise external to a living system is necessary for the development of the living system), film writer Thierry Jousse writes that Godard's use of visual and audio noise – the pinball machine, car horns, etc. – implies that noise is central to communication.[342]

Silverman proposes the dislocation between voice and body as an invitation to think of speech not 'as highly individual and locatable' but intersubjectively, *between* a speaker and listener.' [343] I would add the relation with the viewer and the socio-economic and cultural context. Parker writes that rather than taking individuals' comments at face value, attention must be paid to their location in wider structures of discourse and power if their implications are to be fully understood.[344] In narrative, an insider perspective depends on what is outside the individual as context for the narrative to make sense.[345] Parker, writing of the cultural narratives that shape individual narratives, cites psychologist Bipasha Ahmed: attention must be directed towards the cultural resources that comprise idiosyncratic stories.[346]

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[341] Morrey, *Jean-Luc Godard*, p. 153.

[342] Henri Atlan, *Entre le cristal et la fumée: Essai sur l'organisation du vivant,* Paris: Seuil, 1979, pp. 44–51; T. Jousse 'Godard à l'oreille', *Cahiers du cinéma*, hors série, Spécial Godard: Trente ans depuis, 1990, 40–3, p. 43. Cited in Morrey, *Jean-Luc Godard*, p. 135.

[343] Harun Farocki and Kaja Silverman, 'To love to Work and to Work to Love – A Conversation about "Passion"', *Discourse,* 15, 3, 1993, 57–75, pp. 58–9.

[344] Michele, L. Crossley, *Introducing Narrative Psychology: Self, Trauma, and the Construction of Meaning,* Buckingham: Open University Press, 2000, p. 36. Cited in Parker, *Qualitative Psychology,* p. 74.

[345] Parker, *Qualitative Psychology,* p. 75.

[346] Bipasha Ahmed, 'The Social Construction of Racism: The Case of Second Generation Bangladeshis', *Journal of Community and Applied Social Psychology,* 10, 2000, 33–48. Cited in Parker, *Qualitative Psychology,* p. 73.

In place of individual identity, Godard posits communication – the passing of forms between beings[347] –, which manifests in *Passion* as movement. Much of the action in *Passion* materialises between marked physical locations – when the camera points at these in-between spaces, what we see most often is movement. In the opening sequence, Godard composes the long shot of the driveway with a wide-angle lens. Characters enter the frame in cars and on foot and their paths' cross, generating friction before they disperse. Morrey describes *Passion* as the cinema of an instant; isolated from the past and the future, it has no duration.[348] *Passion* presents the viewer with a cross-section of everything – a presentation that is unlike a linear narrative of the world.[349] Although the opening sequence develops in the time that it is watched, it demonstrates what Morrey refers to as a cross-section of the universe – which I understand spatially and in terms of representative sample – as having no beginning or end, only a middle.[350] Many shots in *Passion* are composed in a similar way as Godard uses pace, rhythm, and sound to narrate (and punctuate) these spaces. This method of exploring the between spaces also effects those places which are marked: As characters move from the factory and take work as extras in Jerzy's film, the characters and the boundaries between the spaces blur and are porous, while remaining distinct.

As *Passion's* characters move between spaces, elements of their characters come to the fore through different bodily actions and gestures. This positioning and framing changes the way they behave and are perceived. As my eyes follow this movement, staging becomes a narrative resource, directing my attention across the frame. As actors enter and exit Jerzy's film set, as rehearsals take place and directions are given, I become more aware of the staging of a film within a film and of characters' transitioning from off-screen/offstage to onscreen/onstage. I relate this to the sociologist Pierre Bourdieu's concept of *habitus* and bodily *hexis*:

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[347] Ibid.

[348] Morrey, *Jean-Luc Godard*, pp. 152–3.

[349] Luc Moullet, 'Suivez le guide', *Cahiers du cinéma,* hors série, *Spècial Godard: Trente ans depuis,* 1990, 104–11, p. 106. Cited in Morrey, *Jean-Luc Godard*, p. 151.

[350] Morrey, *Jean-Luc Godard*, p. 151.

> The *habitus* is a set of *dispositions* which incline agents to act and react in certain ways. The dispositions generate practices, perceptions and attitudes which are 'regular' without being consciously co-ordinated or governed by any 'rule'.[351]

For Bourdieu, these dispositions shape the body and feel natural (they are said to be pre-conscious), yet reflect the social conditions informing their make-up. Watching *Passion,* I became aware of characters' movements through space – in, around, and between different locations. Bourdieu's idea of bodily *hexis*, a product of history and its reproduction, is the organisation of the body in the world and is visible in the body's movements, for example its ways of walking through the world.[352] Yet, significantly, it is the relation between the *habitus* and the social contexts (fields) in which individuals act that creates particular practices and perceptions.[353] This relation between *habitus* and the social context can vary in its degree of compatibility or congruence. Thus, situations may arise when an individual is unsure how to act or may indeed be unable to speak.[354] I am reminded of how I felt lost for words while presenting *Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia* at an HDGC Patient Information Day in Cambridge – unable to speak post-presentation, I felt a crippling dissonance at the incongruence of the multiple social contexts and roles I simultaneously inhabited: that of patient, artist, researcher, sister, and daughter.

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351 Pierre Bourdieu, *The Logic of Practice,* translated by Richard Nice, Cambridge: Polity, 1990, p. 53. [*Le sens practique,* Paris: Les Éditions de Minuit, 1980].

John B. Thompson, 'Editor's Introduction', in Pierre Bourdieu, *Language and Symbolic Power,* translated by Gino Raymond and Matthew Adamson, Cambridge: Polity, 1991, p. 12.

352 Thompson, 'Editor's Introduction', in Bourdieu, *Language and Symbolic Power,* p. 13.

353 Thompson, 'Editor's Introduction', in Bourdieu, *Language and Symbolic Power,* pp. 12–13.

354 Thompson, 'Editor's Introduction', in Bourdieu, *Language and Symbolic Power,* p. 17.

‘Qu’est-ce que c’est que cette histoire Monsieur Courtard?’

The same questioning male off-screen voice directs his question to Monsieur Coutard: ‘What’s this story, M. Coutard?’ The camera cuts from the factory to the film studio. The lighting is as before (strong, warm, artificial) but the viewpoint is different – a low-angle medium shot of four actors, two in the foreground and two in the background. Blackness behind the actors suggests nothingness. The play of light and shadow on the actors’ faces and their elaborate costumes produces a painterly scene. As the camera remains fixed, it reveals the actors’ slight movements, despite their still positions in the *tableaux vivant*.

‘No story. Everything is properly lit, from left to right, top to bottom, and front to back. It’s not a “Nightwatch” but a “Daywatch” lit by a sun already low on the horizon.’ M. Coutard’s intonation rises, peaking on ‘watch’ of ‘daywatch’ creating a tone of wonder. This sense is increased with the arrival of piano music, which continues with a wider range of notes and a quickening tempo as it crescendos.

There is a cut to a medium close-up of an actor. Half of his face is spotlit; the other side is in shadow. Apart from his white frilly collar and the side of his hat, his clothes blend into the black background. The camera, which seems handheld, moves slowly downwards and to the right, blurring the features of the actor until he is out of frame. Rising and falling piano music accompanies the camera’s movements. The camera passes over and focuses sharply on the face of a second actor holding a rifle near to his face. Although his hat is dark, like his facial hair it is textured. He looks down and his face catches the light. The camera moves upwards and to the right, following the barrel of his rifle. The camera moves around the scene slowly up and back towards the left of the *tableaux vivant* focusing on the actors’ faces as it passes over them. Together the light and camera movement make visible and invisible the actors’ faces, revealing what was concealed and *vice versa*.

No Story

Writer and producer Anna Manubens sees absence of linear narrative as a meta-theme in *Passion*.[355] M. Bonnel's response describes not only the composition of the *tableaux vivants*, but also the narrative of *Passion* in its entirety.[356] Contrary to conventional linear narratives with clear formulaic plots, an overarching plotted storyline does not unfold chronologically in *Passion*. Cause and effect relations characteristic of emplotment do not figure. Nothing explains why the factory boss seems to smoke roses, or why the hotel maid performs complex yogic positions while taking room service orders. Harcourt writes that *Passion* is 'full of stories but with no plot to thicken'.[357] Wholeness of narrative plot is foregone by detail, which limits understanding and obfuscates; the masses of detail limits visibility. Aimée Israel-Pelletier interprets montage ('extreme montage') in *Passion* as 'a series of lengthy fragments of significant events and experiences pulled together by images, words and music in montages that evoke a unified vision of events and experiences – a narrative not so much obscure as irreducible'.[358]

Writing about the camera as it moves around the relatively still *tableaux vivants,* Manubens distinguishes the stilling of action and the isolated camera movement, the combination of which, she writes, splits temporality in two: the action and the camera.[359] This splitting of temporality effects temporal progression and restores surface.[360] In terms of the latter (temporal progression is considered in the following section), Manubens draws on Walter Benjamin's association of a cameraperson with a surgeon and painter with a magician, and his idea that while the painter/magician preserves distance with reality, the cameraperson/surgeon does not.[361] The magician

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[355] Manubens, 'Godard's Lingering Camera', p. 216.

[356] Ibid.

[357] Harcourt, 'Calculated Approximations of Probabilities', 1999, p. 12.

[358] Aimée Israel-Pelletier, 'Godard, Rohmer, and Rancière's "Phrase Image"', *SubStance*, 108, 34, 3, 2005, 62–78, p. 36.

[359] Manubens, 'Godard's Lingering Camera', p. 211.

[360] Ibid.

[361] Walter Benjamin, 'The Work of Art in the Age of Mechanical Reproduction', *Illuminations,* translated by Harry Zorn, London: Pimlico, 1999, pp. 226–7 [*Schriften,* Frankfurt: Suhrkamp Verlag, 1955]. Cited in Anna Manubens, 'Godard's Lingering Camera', p. 212.

‘preserves the apprehension of reality as a total picture while the latter [surgeon] moves among its organs’.[362] Manubens resists the conclusion that in *Passion,* the camera – with its powers of analysis and ability to extend perception – penetrates painting by invoking Godard’s conception of the close-up as prompted by emotion and beauty (as opposed to being a strategy for inspection and analysis). Some camera moves create and preserve surface.[363] Manubens writes about Godard’s lingering camera and its celebration of the surface, which it constitutes, as a caress.[364] Recalling a scene from my visit to a pathologist in Porto – we sat together at the microscope looking at HDGC stomach cells, the pathologist exclaiming the beauty of the image – with technology, we saw through to new surfaces, where we derived pleasure – we did not penetrate them.

Drawing on Immanuel Kant’s ideas of beauty and its effects on pleasure, Manubens writes that the solo choreography of the camera, which suppresses action as it moves around Jerzy’s *tableaux vivants*, allows ‘a cinematographic restoration of a sense of duration in perception’.[365] Manubens sees the camera’s movements as a ‘multiplication or re-enactment’ of a contemplative encounter between viewer and painting.[366] By ‘retaining the instant and activating a dilated temporality for apprehension through camera motion’, *Passion* attends to the desire to linger, aimlessly, in contemplation and beauty.[367] Manubens suggests that this lingering in stillness, achieved by the camera’s movement around stilled action, subverts the normative narrative progression of film, which preoccupies Jerzy, defined by Laura Mulvey as:

> Cinema’s forward movement, the successive order of film, merges easily into the order of narrative. Linearity, causality and the linking figure of metonymy, all

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[362] Manubens, ‘Godard’s Lingering Camera’, p. 212.

[363] Manubens, ‘Godard’s Lingering Camera’, p. 213.

[364] Manubens, ‘Godard’s Lingering Camera’, pp. 220–221.

[365] Manubens, ‘Godard’s Lingering Camera’, p. 214.

[366] Ibid.

[367] Ibid.

> crucial elements of storytelling, find correspondence in the unfolding, forward-moving direction of film.[368]

Manubens employs the philosopher Jacques Rancière's term 'aesthetic suspension' in her reading of the 'fragmentary juxtaposition of sequences' in *Passion* (in particular, the camera's lingering movement over stillness).[369] Rancière applies this term to Godard's *Histoire(s) du cinema* (1998), as the liberation of images from their traditional use for representation (when they 'are subordinated to the causal relationality of the plot; when they present its visible effects inviting us to understand their causes and set in motion specific effects, thereby enhancing the perception of cause effect connection.').[370] In place of plot, 'aesthetic suspension' is an alternate relation between signification and visibility based on 'not determining it, of rendering infinite the relationship between visibility and signification and thus paralysing the logic of action. Such is the aesthetic form of suspension, the suspension of action by pathos.'[371]

Ending

Godard writes that 'the only great problem with cinema [...] more and more with each film is when and why to start a shot and when and why to end it'.[372] This seems to be an acknowledgement of the artificiality of bookending stories. In linear narratives, there is always the possibility of going backwards to seek causes and it is unclear where this could end; for example, in Terence Malick's film *The Tree of Life* (2011) it is the big

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[368] Laura Mulvey, 'The Death Drive: Narrative Movement Stilled', *Death 24x a Second*, London: Reaktion, 2006, p. 69. Cited in Anna Manubens, 'Godard's Lingering Camera From *Le Mépris* to *Passion* and Back', *Critical Quarterly*, 53, 2011, 208–24, p. 215.

[369] Jacques Rancière, 'Godard, Hitchcock and the Cinematographic image' in *For Ever Godard,* edited by Michael Temple, James S. Williams, and Michael Witt, London: Black Dog, 2004, p. 214–41. Cited in Manubens, 'Godard's Lingering Camera', p. 216.

[370] Rancière, 'Godard, Hitchcock and the Cinematographic image', p. 216. Cited in Manubens, 'Godard's Lingering Camera', p. 216.

[371] Rancière, 'Godard, Hitchcock and the Cinematographic image', p. 220. Cited in Manubens, 'Godard's Lingering Camera' p. 216.

[372] Jean-Luc Godard, *Godard on Godard,* edited by Jean Narboni and Tom Milne, London: Secker & Warbug, 1972, p. 214 [*Jean-Luc Godard par Jean-Luc* Godard, Collection des Cahiers du Cinéma, Paris: Pierre Belfond, 1968].

bang. Morrey writes that Godard says it is futile to seek out a beginning because you can always go back.[373]

Passion ends with Jerzy abandoning the production of his film *Passion* – which remains unresolved. The characters disperse, mostly going home and/or to Poland. This ending does not offer much closure. I am left wondering whether Jerzy's *Passion* will ever come to completion: if the characters make it home, what Isabelle does with the money paid to her by the factory, if indeed she ever received it, whether Jerzy is with Hanna or Isabelle, and what to make of him leaving with the yogic hotel maid. The ending can also be read as an opening: the characters' lives are in transit to a new beginning. While unresolved in Godard's *Passion*, the making of Jerzy's *Passion* may well begin again under a new director, as there is news of funding from America.

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[373] Morrey, *Jean-Luc Godard*, p. 153.

Scénario du film 'Passion' (Scénario), directed by Jean-Luc Godard [374]

Seeing a script — Video — Touch —
Spatial Arrangement and Movement — Ending

Seeing a script

Godard's *Scénario du film 'Passion'* (*Scénario*) is a video for television. Made shortly after *Passion, Scénario* is Godard's reflection on the process of scripting *Passion* – a visual process of seeing before writing.

Before making *Passion* and *Scénario*, Godard created a brief initial synopsis for the purpose of hiring the actor Hanna Schygulla, which he developed into *Passion. Introduction à un scénario.*[375] *Passion. Introduction à un scénario* is a twelve-page collaged scenario with promotional photographs of his intended actors, drawings, images of paintings (some of which would become *Passion*'s *tableaux vivants),* and text. *Passion. Introduction à un scénario* is accompanied by an audiocassette with musical motifs.[376] Subsequent video footage, shot to develop *Passion*'s narrative, formed Godard's initial video scenario – *Troisième état du scénario du film Passion or Passion: le travail et l'amour: introduction à un scénario* – which he referred to as the 'production of a visual screenplay'.[377] Film writer James Roy MacBean writes of *Passion*'s crew and actors' resistance to Godard attempts to use images in place of a script in *Passion*.[378] Godard recorded improvisational sessions and conversations with the actors.[379] Godard remade his initial video scenario post the production of *Passion* and this became *Scénario:* a retrospective view of the scripting of *Passion*.[380] Godard

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[374] *Scénario du film 'Passion'*, dir. by Jean-Luc Godard, JLG Films, Television Romande, 1982.

[375] Jill Murphy, 'To see a script': Jean-Luc Godard's re-envisioning of screenwriting in *Passion* (1982) and *Scénario du film Passion* (1982)', *Journal of Screenwriting,* 3, 1, 2012, 9–25, p. 15.

[376] Murphy, 'To see a script', p. 15.

[377] Ibid.

[378] James Roy MacBean, 'Filming the inside of His Own Head: Godard's Cerebral Passion', *Film Quarterly,* 38, 1, 1984, 16–24, p. 16.

[379] Murphy, 'To see a script', p. 15.

[380] Ibid.

uses visualisation to envision *Passion* and to retrospectively tell of its fruition. Visualisation is used to look to the future and tell of what is past.[381]

In *Scénario*, Godard speaks about seeing a script, rather than writing a script. The camera, he says, makes the probable possible – he uses it to see if a world could exist. The script creates a probability and the camera makes it possible: an act of discovery over creation. Murphy writes that Godard's open-ended screenplays provide a starting point, not an end point, for narrative.[382]

Video

Godard's use of video for visualisation seems a natural progression from his earlier collaged synopses. In *Scénario*, Godard explores the techniques afforded by video: layering images and sequences, dissolving images and sequences into and onto each other, the screen, and his body. Cross dissolve is a technique used in editing to join images in a different way to the cutting that proliferates in *Scénario*'s montage sequences. Godard's use of cross-dissolve beings a new aesthetic to the use of the conjunction 'and' discussed by Marquez.[383] It allows images to touch in a new way to create new meaning – a meaning less 'open' to different readings than that made with montage, more 'scripted'.

Touch

Scénario is a tactile work – in the sense that touch figures between images, sounds, bodies, Godard, and the screen. Drawing on Jean-Luc Nancy's writing about touch as a contact that is always a spacing, Laura McMahon writes that cinema, by simultaneously inviting and refusing touch exemplifies a sense of touch that takes place as

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[381] This observation – of visualisation used to look to the future and the past – is in accord with the methodological point made in the previous chapter that the expansion of autoethnographic methods to include autobiographical art practice amplifies possibilities for insight and new understanding.

[382] Murphy, 'To see a script', p. 12.

[383] Marquez, 'Art and Women as Thresholds of the Sublime', p. 20.

withdrawal.[384] By presenting tactile and material images and sounds that are ultimately untouchable, cinema foregrounds spacing within touch.[385] Nancy's sense of touch (between viewer and image, and between beings) is not one of fusion or penetration but of being-with[386] – a mutually ungraspable relation to finitude.[387] This being-with, a sense of touch as a contact that is a spacing, can applied in relation to the inbetween; to the interstice between two images (sounds or bodies) *via* the conjunction 'and'. Images can be understood to be placed in contact at the interstice – a contact that is, following Nancy, also a separation. Thus, Deleuze's interstice can be considered as the site of contact and also a spacing. This form of touch – inbetween two things conjoined with 'and' – is not possessive, as exemplified in Manubens' writing about Godard's lingering camera as a caress[388]; or film studies professor Elena del Rio's use of the term 'embrace' in her writing about *Scénario* (about which I write in the preceding section). In this sense, cinema offers touch that will never concretise and thus remains 'perpetually open to the event of a coming-to-presence'.[389]

Spatial Arrangement and Movement

Scénario seems to be shot in Godard's video-editing room. The spatial arrangement shows Godard, the main human presence, orchestrating meaning from the centre of the frame like the conductor of an orchestra.

In one of the primary frame arrangements Godard occupies the bottom middle third of the frame. He sits at a mixing desk with his back to a stationary camera. The viewer sees his silhouette. In front of Godard, occupying most of the frame is a large projection screen. Godard's use of the screen explores its flexible and malleable nature. In one sequence, text appears on the screen, recalling Mulvey's description of the screen, not

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[384] Laura McMahon, *Cinema and Contact: The Withdrawal of Touch in Nancy, Bresson, Duras and Denis,* Oxford: Legenda, 2012, p. 2.

[385] McMahon, *Cinema and Contact,* p. 2.

[386] McMahon, *Cinema and Contact,* pp. 14–15.

[387] McMahon, *Cinema and Contact,* p. 20.

[388] Manubens, 'Godard's Lingering Camera', pp. 220–221.

[389] McMahon, *Cinema and Contact,* p. 25.

as a blackboard, but as a portal. To the right of the screen, in the top right corner of the frame, there is a small monitor on which everything that is in the main frame plays. Above the projection screen is a light area – probably the walls of the room. To the left of the projection screen is large black shelving housing mixing equipment; a small monitor – again, playing back what is seen in the frame – can just be made out. Two blacked out windows may be seen in the top left of the frame. Despite this detail, the spatial arrangements in *Scénario* suggest a process of triangulation – a method of analysing work, of looking and talking about the processes of its making.

Movement – the camera movement, the movement of Godard's body, and the movement in the projected images – is central to the narrative of *Scénario*. Godard conducts *Scénario* with bodily movements particularly gestures of his arms, punctuating its narrative with his breathing in smoking.

Ending

I find the ending of *Scénario* most affecting. Everything climaxes: Godard speaks about now being in the heart of it, where you can invent the sea for the white page. He speaks of the mother waiting and her child. He speaks of the child returning to the mother. On the screen is the blue sea with a man on a pier. As the man walks towards the shore, Godard moves and holds the image of the man in his arms. Godard speaks and there is much repetition of the phrase 'here is'. 'Here is the light, the soldiers, the boss […] here is the light, joy, fear […]' It is an unburdening, a telling that is a release and also healing. It is an ending, death, and a returning. It may be catharsis. I think about the conditions under which someone can tell of experiences in a way that is unconstrained by their audience – questionably an impossible scenario for me because my cognizance of audience, to some extent, modifies my telling.[390]

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[390] I refer back to my earlier discussion of my performance of good health – my reticence to employ narration to normalise unstable, possibly unnarratable, elements of patient experience (see p. 36).

Elena del Rio considers this scene to be a powerful act of embracing, bringing together Godard's body and the screen body 'temporarily in one single corporeal assemblage'.[391] Godard explores word play and free association: Rio notes that the French phoneme 'mer' can mean 'sea' and 'mother', writing that Godard encourages the man on the pier to go home to the outstretched arms of the sea and the mother.[392] The affect of this sequence, writes Rio, is found in the protective manner that Godard puts his arms around the man's body – a gesture that she understands as a 'total, uncompromising belief in the image'.[393]

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[391] Elena del Rio, 'Alchemies of Thought in Godard's Cinema: Deleuze and Merleau-Ponty', *SubStance,* 108, 34, 3, 2005, 62–78, p. 68.

[392] Ibid.

[393] Ibid.

The Joycean Society, by Dora García, 2013

Movement — Intimacy and Distance — A Search for Meaning — Communal Reading — Reading as Therapeutic — Social critique — Pace and Time

The Joycean Society shadows a group meeting in Zurich to read James Joyce's *Finnegan's Wake*.[394] It begins with a black screen. After twenty seconds, a female voice says she is reading about the artist Damien Hirst.

Looking at the black screen, I remember watching Karen Mirza and Brad Butler's 2014 film *The Unreliable Narrator* at the Whitechapel Gallery, London. The film, about the 2008 Mumbai attacks, suggests that its scenes – CCTV footage from the siege, phone conversations between the attackers and their leaders – were performed for news cameras.[395] I was alone in the auditorium when the film began with a black screen, accompanied by increasing layers of audio. Conscious of my immanent train departure, I sat anxiously wondering whether the screen was purposely black or perhaps a glitch with the screening. As time passed, the screen remained black and in this decision I found meaning. The film ended and I left. Passing an attendant on my exit, I enquired about the lack of an image. A glitch. A technician was called and I sat for my second viewing. I found new meanings. Later, reading critical texts on the work, I see new meanings. Meaning is key in *The Joycean Society*.

There is a cut from black. Two male and one female voice, now on screen, discuss Hirst. They talk about his prices dropping, living in privilege, and then some advice, a warning, is offered to artists. The handheld camera captures the people talking in medium close-up. One of the men faces the camera; he is sitting with his elbows on the table, his hands loosely clasped together at his chin. At the front right of the frame, a second man's face appears out of focus, he briefly turns towards the camera. Between

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[394] *The Joycean Society,* dir. by Dora García, Auguste Orts, 2013 [video, colour, 16:9, 53 minutes].

[395] *Karen Mirza and Brad Butler: The Unreliable Narrator, Artists' Film International,* Whitechapel Gallery 2017 <http://www.whitechapelgallery.org/exhibitions/artists-film-international-karen-mirza-and-brad-butler/> [accessed 28 June 2107].

the two men there is some movement and I realise that the unseen female between them is folding the pages of the newspaper she is reading. The camera moves slowly downwards, revealing the tabletop, the newspaper, and the hand holding it as I hear its pages crinkle. The camera moves upwards. A third face appears in between the two men; it is the woman who was reading the newspaper and speaking about Hirst. The camera is still momentarily, the focus is slowly adjusted and the profile of the woman sitting between the two men comes into sharp focus. The three continue talking and although they disagree, their tone is playful. I notice their different accents. Movement in the background signals people assembling. Blurred movement in the foreground – a fourth figure entering – obscures one of the reader's faces. Ambient noise in the background – people moving, steps, and creaking – heightens my sense of a beginning and arrival.

The camera moves to settle on a profile of the woman's face as she continues talking about Hirst. Her face is in focus. In the background there is a big open wooden door, a sheet of white A4 paper with typed writing is pinned to it. The camera moves unsteadily around and upwards. The opening of the door fills most of the frame. Although what fills the doorway is out of focus, I can make out a figure. The camera shakily returns to the three faces at the table. With these clues as to a meeting room at the opening of the film, I have a sense of waiting for a beginning.

The scene cuts abruptly to a close-up of Milton Hebald's bronze statue of Joyce. The camera is now still. It is a bright snowy scene illuminated by natural daylight. The statue is captured from the same point of view as the readers' faces earlier – in profile, from the chest up, its face in focus. The background – the ground blanketed in snow, trees and branches – is out of focus. Snowflakes fall softly and slowly in tangential directions, the bronze statue remains, untouched for the snow does not settle there. The only movement is that of the few snowflakes gently falling, blowing around on the wind and the patterns of light and shadow that move almost imperceptibly across the surface of the statue. These tiny, gentle movements accentuate the stillness in the scene.

There is a shift in perspective and now the camera captures the statue of Joyce in the middle right of the frame, in the foreground is Joyce's grave, surrounded by a low stone wall. Though it is not snowing, there is snow everywhere, bringing to mind Joyce's short story *The Dead*. Deep drifts of snow are visible on the bronze statue; branches of pine can just be seen under the snow by the stone wall. The snow has been cleared from Joyce's grave.

Another shift in camera position: the statue of Joyce, from the waist upwards, occupies the centre of the static frame. Its face is in profile. Snow has gathered on the top and back of the statue. The light is different. It is dull and the surface of the statue, unlike in the previous shots, in which it is shiny, is now matt. The weathering of its surface is discernible.

Accompanying the visual plane is the sound of the readers' chatter. It seems they have not started reading properly. One of the readers puts a humorous medical question to the group, based on a review of a book (about how you tell if someone is dead before they are buried) that he read in the *Times Literary Supplement* of 4 January. There is much laughter and some discussion. As I pay attention to the readers' conversation, my eyes cannot settle on the still snowy grave scenes. My attention is split and I do not find the stillness contemplative.

Movement

The movement of the handheld camera in these first scenes is typical of *The Joycean Society*. The camera follows the readers' activities, moving around the room.[396] Yet, the camera is restless; it does not settle long on the readers' faces.[397] At times, its movements are jerky as it crosses the table causing a blur of movement. Often, the reader speaking is in focus and the others are blurred, or the reader speaking is heard

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[396] The camera movement resembles the movement of my eyes in a reading group as I look at my text, write notes, look up from my book and observe other readers.

[397] I am quite tolerant of this but wonder how much distraction it might cause for others, as the movement is far from seamless.

and the visual plane shows readers listening and looking. Focusing is sometimes subtle but more often it is jarring, as the camera, which seems to be on autofocus, focuses in and out until it finally settles.

The movement of the camera is unlike that of the readers in their activity of communal reading: The readers are quite still relative to the camera movement. Most of their bodily movement is in the upper body: the readers sit at the table, their hands and arms move as they hold pencils, pages, and books; they shift in their chairs; and turn to look at the others, their books and notes, and sometimes towards the camera. When capturing readers reading, the camera is positioned at the same height as the readers, as it if it were one of them (a fidgety one). The camera position and movement contribute to a feeling of closeness and intimacy with the readers.

Intimacy and Distance

Intimacy derives also from the readers' bodily movements, which in light of their not acting a rehearsed performance, display everyday rhythms of life. In an interview with journalist Kellie Moore, García speaks of the challenges she had to overcome filming in a small room with little light to ensure that the readers did not act.[398]

Sound is used to create intimacy. Small microphones, which may include contact microphones, are used to capture detailed sound. The microphones sometimes come into view on the table around which the readers sit. García describes the challenge of recording the sound to create intimacy between the viewer and readers:

> The second one, but was easily overcome by the talent of the sound man, was to record the sounds in such a way that you would feel the space, and the position of people, so that you would really feel that you were in a circle of people talking.[399]

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[398] Kellie Moore, *Exploring one of literature*'s *most complex works in 'The Joycean Society'* <http://kbia.org/post/exploring-one-literatures-most-complex-works-joycean-society> [accessed 28 June 2107].

[399] Moore, *Exploring one of literature*'s *most complex works in 'The Joycean Society'*, KBIA, Mid-Missouri Public Radio, 2014 <http://kbia.org/post/exploring-one-literatures-most-complex-works-joycean-society> [accessed 28 June 2107].

Camera movement and position, authenticity, and sound contribute to the sense of proximity between the viewer and the viewed – blurring the distinction between these positions.

The camera is used as a tool of observation in a documentary style. It zooms in to pay extraordinary attention to detail, capturing the readers, their faces and expressions; sideways glances, eyes, wrinkles, ears, hairs, spectacles, backs of readers' necks, ageing hands, hands holding pens, a ring on a finger, finger nails and their white moons, fingers turning pages – forward and then backwards again; the texts, the marginalia, the pages, the scribbles, numbers, and crossings out; the penned lines and the connections drawn, the neat ink borders, ink blots; small gestures – intentional, functional, choreographed – eyes looking at books and looks between readers; little piles of books, temporary cities, opened like concertinas; chests rising and falling, breathing.

The philosopher Aaron Schuster, in an interview with García on *Vdrome*, writes that as well as the intimacy created in *The Joycean Society,* '[…] there is also a sense of an almost clinical distance, a kind of anthropological documentation of this lost tribe of dedicated readers in the Swiss wilderness'.[400] The capturing of detail contributes to this sense of observation and with it, a sense of distance. The ethnographic, technical, and artistic methods employed in *The Joycean Society* produce a sense of both intimacy and distance between the viewer and the viewed. I feel both part of and separate from that community.

Responding to Schuster, García says that she filmed the readers as 'incarnating one of the most notorious episodes in *Finnegans Wake*: Mamalujo – the four old men endlessly discussing the text. When they stop reading the text, the world will collapse.'[401] I am

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[400] Aaron Schuster, 'Dora Garicía, The Joycean Society', *Vdrome*, Mousse Magazine and Publishing, Milano, Italy, 2016 <http://www.vdrome.org/garcia.html> [accessed 28 June 2107].

[401] Dora García, Aaron Schuster, 'Dora Garicía, The Joycean Society', *Vdrome*, Mousse Magazine and Publishing, Milano, Italy, 2016 <http://www.vdrome.org/garcia.html> [accessed 28 June 2107].

reminded of Scheherazade in *One Thousand and One Nights* – telling stories to stay alive.

A Search for Meaning

> tenpounten on the pop for the daulphins born with five spoiled squibs for Infanta; a letter to last a lifetime for Maggi beyond by the ashpit; the heaftiest frozen meat woman from Lusk to Livienbad for Felim the Ferry; spas and speranza and symposium's syrup for decayed and blind gouty Gough; a change of naves and joys of ills for Amoricus Tristam Amoor Saint Lawrence; [...] a guilty goldeny bellows, below me blow me, for Ida Ida and a hushaby rocker, Elletrouvetout, for Who-is-silvier — Where-is-he?;[402]

Fritz Senn, director of the Zürich James Joyce Foundation, says that it is good. The reader stops. Fritz says again it is good, that again they are all small items. Another reader says that maybe that is where she operated: beyond the ashpit. Another (is it Fritz's voice?) says the man might be Julius Maggi, the inventor of Maggi soup. There is hushed giggling. The readers wonder if there is a man there, they think there could be and then decide that there is, now.

The close reading continues in this manner: word-by-word, sentence-by-sentence, section-by-section; with pauses to consult secondary sources – letters and guides. Readers express degrees of certainty about the possible meaning of what has been read through intonation, stress, and modal verbs – imagining what could be. They use phonetics, finding words that sound like the words they read, employing word play to travel from 'bellow', to 'below', and then to 'blow'.

In a voice-over, Geert Lernout, an academic and one of the readers, refers to a conversation between Joyce and the Irish writer James Stevens, who, Lernout says, was going to take over writing *Finnegans Wake* from Joyce. Of *Finnegans Wake,* Joyce is

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[402] James Joyce, *Finnegans Wake,* London: Faber & Faber, 1939, p. 211.

said to say: ‘Well, it is just a number of rules, and if you know the rules, anybody can do this.’ Lernout finds strange the idea that it is a mechanism, a machine such as car, where who is driving is of no importance. Lernout says that Joyce said he wanted to exhaust language, which suggests to Lernout that it is more of a logic than a path.

Lernout says, in a talking head shot, that Joyce read an introduction to a translation of the Koran and noted that each word in the Koran is supposed to have seventy different meanings, using this in *Finnegans Wake*. Despite having this knowledge, Lernout advises not ascribing to the ideology but describing it and seeing how far it gets you.

At times readers find something close to meaning, at others they do find sense. Meaning is explored without being a final palpable objective, which seems to compel their reading. The historian Christa Maria Lerm-Hayes writes of ‘the ways in which finally not-understanding is implied, taken for granted, and thus valued’.[403] This implication and acceptance of not-understanding can be understood in relation to the multiplicity of meanings to be found in Joyce, which, writes Lerm-Hayes, hold great appeal for people attracted to an understanding of research that does not insist on telos of predefined meaning.[404]

Fritz, talking to camera, says that though the readers do not recognise a pattern they do not stop reading. Fritz acknowledges the disappointment they feel when they cannot break a pattern or find meaning; however, in these instances, they can share it.

Communal Reading

The Joycean Society is about a community of readers, about the activities of reading and listening collectively. Readers share their knowledge and understanding in a manner that is collaborative and supportive. There is no hierarchy in the group. The scale of the shots of the readers reading is democratised, as each reader is filmed in a similar way.

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[403] Christa Maria Lerm-Hayes, *Writing Art and Creating Back: What Can We Do With Art (History)?* Inaugural lecture 537, Amsterdam: Amsterdam University Press, 2015, 1–29, p. 9.

[404] Ibid.

Open to all possible interpretations, in light of its difficulty, *Finnegans Wake* is appropriate for communal reading to happen in this way – it is as if anyone can participate in the search for meaning. Even I, a first time communal reader of Joyce, felt comfortable to participate in communal reading with the Leeds Finnegans Wake Reading Group, offering an interpretation of Joyce's use of 'proud of', as a term used in carpentry meaning that something protrudes; being neither flush with nor shy of.

In García's lecture in Leeds Beckett University's 'Performance and Uncertainty' symposium (4 March 2017), programmed by Kiff Bamford and Harold Offeh, at The Tetley, Leeds, García spoke of the self-sufficiency of language in *Finnegans Wake*. For the readers in *The Joycean Society* language is sufficient – it is the material of their communal activity, the basis from which they derive enjoyment. Communal reading in *The Joycean Society* is reading aloud. Readers and listeners take pleasure in the sound of language. I read aloud with the Leeds group because the readers wanted to listen to someone read *Finnegans Wake* aloud who had not done so before. 'That would be me' I said. Reading in *The Joycean Society* is joyful. I too enjoyed reading with the Leeds group – the mental stimulation, the interaction with others, their faces, smiles, and glances, the sound of the words, the accents, and musicality of the voices, the shared quest. I also enjoy watching *The Joycean Society*. I have learnt that narrative does not have to make sense to be enjoyable or indeed to be endured. This understanding offers a way of experiencing the world.

Reading as Therapeutic

Fritz talks to camera about the reading group as therapy: readers can say whatever they want. Fritz sees value in the possibility of interacting with a text, particularly helpful, he says, as a substitute for those who are not very successful in life – with lives that are not emotionally full, that if he were happier he would be a banker. Fritz talks about his participation in the reading group 'along almost Freudian lines' – that culture is a substitute for pleasures denied.

Listening again to Fritz and thinking about the therapeutic possibilities of studying a text through reading and re-reading *ad infinitum*, I recall in how in her lecture García spoke of her work *The Sinthome Score* – which I saw in her Leeds exhibition *These books were alive, they spoke to me! The Sinthome Score* – a performance and installation work – is a translation of Jaques Lacan's seminar 'Le Sinthome' with illustrated movements for each of its chapters. It is performed by two people – one reads, the other moves. García says that *The Sinthome Score* explores repetition and memory, specifically the idea of not remembering but repeating and working through. García speaks of the importance of screen memories to *The Sinthome Score* – 'fake memories used to pretend you remember but which never happened'.[405] In Freud's essay 'Screen Memories', early memories are screens for later events.[406] In such cases, an early memory is only incompletely retained – what is important in the original event is suppressed, thus the memory will often appear trivial.[407] (In later work, Freud writes of screen memories as early events screened by later memories.[408]) *The Sinthome Score* explores the idea in psychoanalysis that nothing is erased from memory; that refused memories will surface as repeated action.[409] This symptom (the thing that is done – in this case the reading and the moving in a feedback loop) through practice, keeps the subject (the body pierced by language) from going mad.[410] Schuster says:

> If for Lacan *Finnegans Wake* exemplifies the possibility of creating one's own private symptom in language, it would seem that for this group, the Wake itself functions as a kind of socially shared symptom, which they are constantly working through – 'Enjoy your symptom!' as the title of one of Žižek's books goes.

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[405] Dora García, 'Performance and Uncertainty Symposium', developed by Leeds Beckett University, 4 February 2017.

[406] Editors' note, Sigmund Freud, 'Screen Memories', in *The Standard Edition of The Complete Psychological Works of Sigmund Freud,* translated by James Strachey, in collaboration with Anna Freud, assisted by Alix Strachey and Alan Tyson, Vol. III, London: Hogarth Press, 1962, 301–322, p. 302 [*Mschr. Psychiat. Neurol.,* 6, 3, 1899, 215–30].

[407] Freud, 'Screen Memories', pp. 306–307.

[408] Editors' note, Freud, 'Screen Memories', p. 302.

[409] García, 'Performance and Uncertainty Symposium', 4 February 2017.

[410] Ibid.

Watching *The Joycean Society* I think about the book, about art, as a refuge. I think of the reading group as an interstice. Readers arrive, read together, and leave. The viewer learns nothing about where the readers will go as their reading and the film ends. Nothing is offered to help the viewer place this experience in the readers' biographies. My father found this disconcerting. Confused, he wanted to know from where the readers had come and, presumably in response to their accents, when would they be returning. *The Joycean Society* can be read as a document of an interstice: The readers occupying a place in-between what is before and what comes after. Their meeting belongs neither to before or after. In this in-between space, readers find a way of being, of occupying a space in time. It is not a becoming but a being-with.

Social critique

The press material for the Venice Biennale 2013 proposes *The Joycean Society* as a philosophical tool for social critique.[411] In *Art Review*, the curator Maria Lind writes:

> Stealth activities like the ones of the Joycean Society's reading group and its stubbornly cooperative investment and inconclusive aim comprise nothing less than an act of resistance to current pressures, whether conscious or unconscious.[412]

I understand Lind to mean that the film critiques perceived current pressure to invest individually in achievable goals and aims – a narrative of personal progress and betterment, common in today's neoliberal societies.[413] *The Joycean Society* does not offer a solution or an answer, yet meaning is made and deliberated. In so doing, *The Joycean Society* offers an alternative, an engagement, which as Lind writes is a

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[411] *Dora García: The Joycean Society Venice Biennale,* from press information, Universes in Universe, Berlin: Dr. Gerhard Haupt and Pat Binder, 2013 <http://universes-in-universe.org/eng/bien/venice_biennale/2013/tour/piac_dora_García> [accessed 28 June 2107].

[412] Maria Lind, 'The Triumph of the Nerds: Maria Lind on Dora García and the Joycean Society's readers group', *Art Review*, September 2014 <http://artreview.com/opinion/september_2014_opinion_maria_lind/> [accessed 28 June 2107].

[413] Sjoerd-Jeroen Moenandar, 'Introduction', in *Stories of Becoming: Using Storytelling for Research, Counselling and Education*, edited by Sjoerd-Jeroen Moenandar and Lynn Wood, Nijmegen: Campus Orleon, 2017, vii–xxviii, p. viii.

‘stubbornly cooperative investment’ with an ‘inconclusive aim’.[414] In *The Joycean Society,* Lind sees an act of resistance; the activities of group reading do not serve current pressures – for production, achievement, progress, and betterment.[415]

The pleasure readers derive from communal reading can also be viewed as an act of resistance: it shows the possibility of pleasure in what might be perceived as an activity useless to the functioning of capitalist society. In *Communal Luxury*, Kristin Ross writes of one of the Artists’ Federation’s use of the term ‘Communal Luxury’ to counter the ‘*misérabilisme*’ of Versaillais portrayal of life in Paris at the time of the Commune, with the maxim that everyone can share, not in misery, but in the best.[416] Ross writes of the resemblances between how life is lived today under contemporary capitalism and how it was lived in the nineteenth century by those who created the Commune.[417] Further resemblances can be seen between the readers’ activities in *The Joycean Society* and those of the Communards – Ross cites Rancière writing about the poetry of workers: ‘It is not through its descriptive content nor its revindications that worker poetry becomes a *social* oeuvre, but rather through its pure act of existing.’[418]

Pace and Time

The Joycean Society is filmed, largely, in real time – a technique associated with the documentary style of *cinéma vérité*. This lends a particular pace to the work, one found in many artists’ films, and one in opposition to the faster pace of Hollywood feature films or indeed, to many digital patient narratives which span whole lifetimes – even generations – in minutes.

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[414] Lind, ‘The Triumph of the Nerds’, *Art Review*, September 2014 <http://artreview.com/opinion/september_2014_opinion_maria_lind/> [accessed 28 June 2107].

[415] This may not be the case – the readers’ activities may function to sustain the dominant culture if their activity enables them to then better participate in the society, whose pressures Lind suggests they resist.

[416] Kristin Ross, *Communal Luxury,* London: Verso, 2015, pp. 64–65 [*L’Imaginaire de la Commune,* Paris: La Fabrique, 2015].

[417] Ross, Communal Luxury, p. 3.

[418] Jaques Rancière, ‘Ronds de fumé (Les Poètes ouvriers dans la France de Louis Philippe)’, *Revue des sciences humaines,* 41, 1983, p. 190. Cited in Ross, *Communal Luxury,* p. 50.

On completing the text, the readers begin again – a cyclical process of reading and re-reading. As one reader says, *Finnegans Wake* is the ideal book for continuation. The last word in the book is 'the' and the first word is 'riverrun'. The circularity of *Finnegans Wake* is mirrored in the groups circling around meaning and more literally in the shape of their positions seated around a table. Meaning is deliberated. Time is acknowledged.

Towards the end of *The Joycean Society* Fritz Senn, talking to camera, says that it took eleven years to complete the first sentence-by-sentence reading of *Finnegans Wake*, a time during which, Senn says, people came and people left. The camera shows objects that bear the passage of time: the books at their corners, spines, marginalia, and notes bearing witness to previous readings. *Finnegans Wake*, its readers, the texts, the group, the grave, and the bronze statue, age and endure time. These details do not obfuscate, rather they encourage contemplation of endurance through time. Readers refer to time passing; at one point, a reader clarifies his understanding of 'recent' as including reference to a past time of up to forty years. Mid-way through the film, one reader tries and fails to remember the name of the novelist who wrote *Roxanna*.

Schuster writes that 'one of the things that is wonderful in this film is its attention to the slow, meandering, uncertain, sometimes funny and sometimes painful art of reading'.[419] Schuster's observation of the film's attention to 'the slow and meandering' reminds me of the filmmaker Víctor Erice's pejorative use of the term 'amnesiac' to describe the effect of fast-paced narrative sequence sequences on the viewer. Writing about Erice's *El Sol de Membillo* (*The Quince Tree Sun*) and Abbas Kiarostami's *Zire darakhatan zeyton* (*Through the Olive Trees*) Linda Ehrlich focuses on the two directors' capacity for resistance to the 'alleged expectation of film viewers who'd like something new, different, and surprising in every scene'.[420] Ehrlich writes of the trust Erice and Kiarostami place in their viewers' ability to appreciate the 'pleasure of inner recall

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[419] Aaron Schuster, 'Dora Garicía, The Joycean Society', *Vdrome*, Mousse Magazine and Publishing, Milano, Italy, 2016 <http://www.vdrome.org/garcia.html> [accessed 28 June 2107].

[420] Linda C. Ehrlich, *The Cinema of Víctor Erice: An Open Window*, Lanhan, MD: Scarecrow Press, 2007, p. 287.

produced by the film from scene to scene, and not on the linear, amnesiac principle of effacing one sequence by the next'.[421]

Distant church bells are heard periodically. The bells are most noticeable at the end of the film when the readers decide that it is time to stop reading so that they can sit for an agreed period of silence – a silence that one reader says is needed after all the talking. The camera pans around the table from left to right and back again, pausing on the readers who look up from the table, their books, and notes. I find this scene moving. The readers gaze upwards and seem lost in thought. There is stillness and weight in this scene, contrasting with all the frivolity and playfulness of earlier. This ritualistic silence is interrupted, but not obtrusively, by the church bells, which brings the readers and me back to where we are. I am reminded of an old friend whose watch beeped every hour – he said it kept him in reality.

The camera focuses on a map and pictures on the wall, and books on the bookshelves, blurring the readers' faces in the foreground and which are no longer in full view. The camera moves down and back around the table to show the readers' hands begin to move before they start to get up and begin to leave the room. The bells continue though the readers' voices cannot be heard – I am not sure if they are not speaking or whether they have now been removed from the film's audio track. The bells suggest time and its abstract, non-narrative measurement with clocks. In *The Joycean Society*, the activity of reading comes to an end, the readers mark this with a shared silence, and then the film ends. Although the film ends, it is not the end of the story of the readers, the text, the grave, the statue, and the reading sessions.

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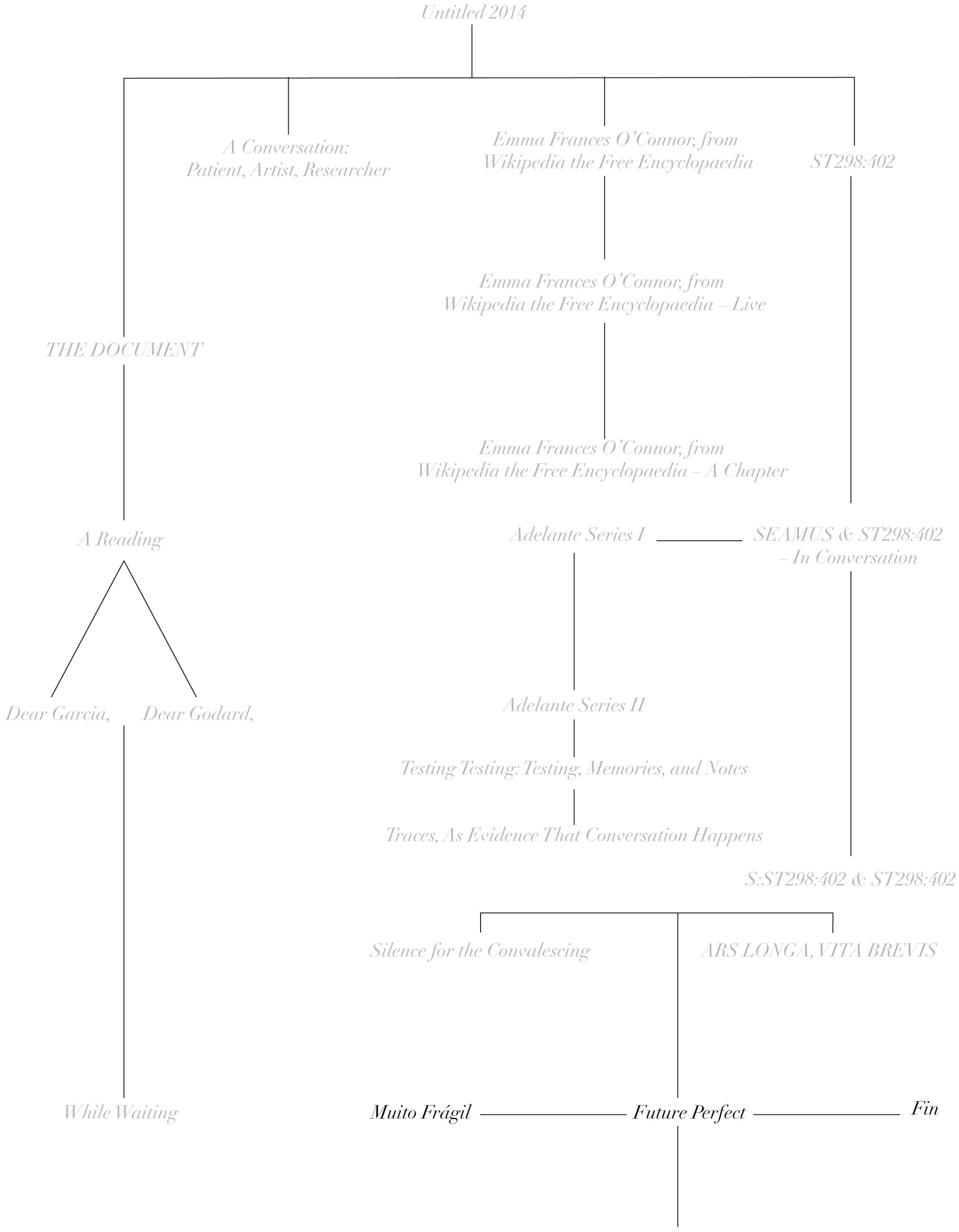
[421] Ibid.

PÉ DE GRUE —— PEDIGREE IV



PÉ DE GRUE ———— PEDIGREE IV

Muito Frágil: A Self-Contract — Future Perfect — Fin —While Waiting

Muito Frágil: A Self-Contract

Muito Frágil: A Self-Contract is a self-contract and a series of five postcard images. The images detail an installation of artefacts – cordoned off with white packing tape with red lettering that reads MUITO FRÁGIL – from the journeys that I have taken to locate my stomach. The work explores my experience journeying to find my stomach, 'trying on' the quest narrative, and responds to the need for an ethics of self-care in autoethnographic practices directly in the text. The images document and detail the ingredients of my journeys – my suitcase, travel itineraries, plans, travel tickets, mementos, shells, charms, maps, business cards, brochures, newspaper clippings, exhibition catalogues, hospital letters, personal letters, photographs, lists, prescriptions, and other travel ephemera. The packing tape ominously cordons off these objects, suggesting a forensic looking and lending a clinical feel to the work, which is troubled by their position as postcards.

Future Perfect

'Where are the stories of failure?'[422] *Future Perfect* is a maquette for a book about the film that I could not make on my quest to trace the journey of my stomach. It features stills from the film and writing. *Future Perfect* addresses and circumnavigates the problem of closure. There is no transformative or happy or sad ending – a critique of master narratives as fictions to make something bearable. There is an ending, but it is also an opening, or beginning for I propose making the film in the future. I think about Scheherazade in *Arabian Nights*, telling stories to stay alive. Post Ph.D., I will take my *Future Perfect* maquette to a designer to work on for publication.

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[422] Lisa Diedrich, *Treatments: Language, Politics, and the Culture of Illness,* Minneapolis, MN: University of Minnesota Press, 2007, p. 54. Cited in McKechnie, 'Anxieties of communication', p. 122.

Fin

Fin is a video work with sound. It is to be installed in a gallery as a small projection (less than 1 metre by 0.75 metres) to facilitate an intimate viewing experience. It will not be possible for a viewer to experience *Fin* in its entirety as the duration of the video will always be longer than that of the exhibition. *Fin* will also remain unfinished, as I keep adding footage to the video.[423]

The raw footage from this work is all the video I have taken over the course of my doctoral work, arranged chronologically with minimal post-production. The material includes: video shot on my DSLR – handheld footage and shots using a tripod; footage from a gopro camera; and video footage from the 'photo booth' program on my laptop. Much of the footage features me, or is from my point of view; and documents my journeys, experiments in making … my daily life.

Dr Rachel Garfield, in her lecture for the Transmission lecture series *Who is an Artist?*, speaks about the valences, hierarchies, and legitimacies: what, for example, can an artist legitimately make work about (or not); how are artists positioned and how do they position themselves (further explored in Garfield's writing about art), and who creates these terms. Questioning how an artist can make art when s/he is isolated or when with child, Garfield makes reference to feminism and second wave feminism and an associated sophisticated do-it-yourself kitchen table aesthetic: the art that it is possible to make under very different, often difficult conditions – at the kitchen table.[424] Elsewhere, Garfield further defends this aesthetic, which, like many women and the vast history of feminist art practice, is so often written out of art history, against prejudices

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[423] *The Inoperative Community,* 3 December 2015 - 14 February 2016, Raven Row, Serge Bard, Eric Baudelaire, Ericka Beckman, Cinema Action, Patrick Deval, Lav Diaz, Mati Diop, Stephen Dwoskin, Luke Fowler, Jean-Luc Godard, Jean-Pierre Gorin, Johan Grimonprez, Marc Karlin, Stuart Marshall, Anne-Marie Miéville, Pere Portabella, Yvonne Rainer, Jackie Raynal, Anne Charlotte Robertson, Helke Sander, Jon Sanders, James Scott, Albert Serra, Leslie Thornton, Humphry Trevelyan. Curated by Dan Kidner <http://www.ravenrow.org/exhibition/the_inoperative_community/> [accessed 28 June 2107].

[424] Rachel Garfield, Transmission Lecture series *Who is an* Artist? 31 January 2017 <http://extra.shu.ac.uk/transmission/transprog.html> convened by Sharon Kivland, TC McCormack, Hester Reeve, and Julie Westerman, Fine Art, in association with Site Gallery, Sheffield.

levelled against it, often due to their lack of funds.[425] Rather, Garfield emphasises how meaning, as well as new ways of making, can come from this aesthetic. Philomène Hoël's installation *Keep it Longer* (Gallery SO, London, April 2017) might be considered a recent example of this aesthetic practice. My work *Fin* relates to this aesthetic – much of the video material is that I could make by my bedside.

I am thinking about closure and alternatives: tactics for the everyday – I live with the wretchedness, without expectation of a happy ending. I notice that my making used to function as a means of escape and hidden narratives. Now, it is also a practice of *being with*. I think of the title of Roberto Bolaño's text *Illness + Literature = Illness*.[426] I remember the exhibition *The Inoperative Community*, which takes its title from Jean-Luc Nancy's essay of the same name, and consists of fifty plus hours of video footage – more than a visitor is able to see. I recall my director of studies, Sharon Kivland, bringing to my attention the end of Samuel Beckett's *The Unnamable:*

> You must say words, as long as there are any, until they find me, until they say me, strange words, strange sin, you must go on, perhaps it's done already, perhaps they have said me already, perhaps they have carried me to the threshold of my story, before the door that opens on my story, that would surprise me. If it opens, it will be I, it will be the silence, where I am, I don't know, I'll never know, in the silence you don't know, you must go on, I can't go on, I'll go on.[427]

While Waiting

This work documents my waiting. I will have posted letters to Jean-Luc Godard and Dora García and I wait for a reply. *While Waiting* will employ the film techniques that I learnt through repeatedly watching *The Joycean Society*. Close-up video and sound

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[425] Rachel Garfield, 'Symposium: Women's Filmmaking in Contemporary Britain - Film Intro and Provocations', ICA London, 2015.

[426] Roberto Bolaño, 'Illness + Literature = Illness' in *The Insuffrable Goucho,* translated by Chris Andrews, London: Picador, 2015 [*El Goucho Insufrible,* Barcelona: Anagrama, 2003].

[427] Samuel Beckett, *The Beckett Trilogy: Mallow, Malone Dies, The Unnamable,* London: Picador, 1979, p. 381-2 [London: Calder, 1959].

recordings in real time will observe conversations between others and me about waiting for replies. The same still scene, filmed from my window, will chart the seasons passing. A handheld camera will capture my movements (not rehearsed performances) through daily activity lending a rhythm to the work; my chasing after signs and consequent magical reasoning (for example, ‘if García exhibits in the UK, she will definitely think to reply’...) will constitute slight changes in pace. The film might be read as a coming-to-terms with a not knowing if there will ever be a reply, and in so doing, like the reading of Joyce, it develops its own momentum and new meanings.

Patient Narrative Re-imagined

Adelante — In Summary — Contribution to Knowledge — Implications and Further Work

Adelante

> *The meaning of the journey emerges recursively: the journey is taken in order to find out what sort of journey one has been taking*.[428]

The final edits of this thesis were written in The University of Sheffield Medical School Library. Located in the Royal Hallamshire Hospital, it is the closest library to home and a rare silent library in Sheffield.[429] A recent detour from the library to the hospital chemist led me down a hospital corridor that I knew well: the coloured lines on its floor have held my attention for much of my Ph.D. and feature in many of my works. Having climbed the main stairwell and set off down my corridor, I stopped dead. The lines had been removed and the walls freshly painted (dark grey and lime green). I thought I must have made a wrong turn. Searching for traces of the presence of the lines, I could just make out remnants of the black tape. As I stood stationary in the middle of the corridor, I wondered if I was the only one who seemed lost – at a loss – by their absence.

As I conclude my doctoral work, I think about the coloured lines and their timely removal from the hospital corridor floor. Having previously found their presence absurd – never understanding their purpose or where they led – I realise that they have anchored me; that I had found meaning in meaninglessness. Reflecting on the desire to find meaning, I recall the words of Sartwell (cited earlier in 'Patient Narrative Part II' on page 42). In *End of Story: Toward an Annihilation of Language and History,* he writes:

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[428] Frank, *The Wounded Storyteller*, p.117.

[429] I have developed a new relation with the hospital: I enter, regularly, with a purpose other than attending clinic appointments, to share a space with doctors in training.

> Narrative comes apart at the extremes […] it comes apart in ecstasy, in writhing pain, at death. But it has already also come apart everywhere, all the time, […]. What narrative is inadequate to is not just the shattering moment, but the moment of indifference […] Pull yourself away from significance for a moment and let yourself feel the sweet, deep, all enveloping insignificance all around you. And take comfort in your own insignificance; take comfort in the triviality of your culture; take comfort in the triviality of your life-project and your failure in realising it.[430]

I begin my concluding chapter with this reflection before I recount the lines I have followed and those I have not, offering the insights that have been made as contributions to knowledge, reflecting on the implications of the study, and proposing future work.

In Summary

In *The Body in Pain* Elaine Scarry explores the idea that the reality of pain escapes, resists, and destroys language, causing feelings of bemusement in both the sufferer and onlooker.[431] Taking this as a line of enquiry, the rationale for this doctoral work began with the desire to better articulate my experience as a carrier of the CDH1 genetic mutation. Frequently asked by researchers working on the Familial Gastric Cancer Study in Cambridge to share my experience, I felt the import of articulating patient experience of genetic medicine for others – to further understanding of how genetic medicine is experienced.[432]

In the initial stages of this work, I immersed myself in the works and processes of artists, filmmakers, and writers attending to illness. Some of these works are discussed in the clinical field and literatures in the medical humanities – the work of Jo Spence,

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[430] Sartwell, *End of Story,* p. 65.

[431] Scarry, *The Body in Pain,* 1985.

[432] The qualitative interview study 'Decision-making about risk-reducing surgery for HDGC' aims to describe individuals' experiences of undergoing risk-reducing surgery.

Derek Jarman, Deborah Padfield, Brian Lobel, Christine Borland, Stelarc, and Orlan, as indicated. Reflecting on how the precursors to this work – Jo Spence and The Hackney Flashers, Lynn Hershman Leeson, Steve Dwoskin, Derek Jarman, and Daria Martin (to name a few examples) – deal with illness, led to the realisation that experience of genetic medicine, being distinct from experiences of illness, would require a new set of approaches for its exploration and articulation.

Analyses of extant patient narratives led to the realisation that most visible narratives of genetic medicine are seldom self-authored and heavily inflected by contextual factors, making it difficult to determine the purposes for which they are written and how they are received. My search for concrete examples of genetic patient narratives has revealed the largely inaccessible nature of what appears to remain a predominantly private discourse. Having met others with the CDH1 mutation, I learnt that some people choose to keep private their experience of genetic medicine – sharing it only with close family members – partly due to reasons related to stigma, which may play a part in explaining why narratives of genetic medicine are seldom shared.[433] This invisibility of genetic patient narratives threatened to impede my navigation of the genre and I have been unable to provide a 'sophisticated account of the genre'.[434] I found the genetic patient voice to be very quiet indeed. In attending to the need for an expanded discussion confronting the contested contemporary definitions and uses of patient narratives, I lay the foundations on which a more comprehensive account of genetic patient narrative – its current uses, (lack of) definitions, functions, forms, and purposes – might be built. Further research should be undertaken to provide a full account of the genre.

Notwithstanding this limitation, analyses of existing patient narratives and critiques of narratives, facilitated enquiry into how these narratives are created, and how narrative is used to better understand patient experience. A historical contextualising of patient

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[433] For a discussion about the framing of genomics in stigma and challenge see: Rachel A. Smith, 'Picking a Frame for Communicating About Genetics: Stigmas or Challenges', *Journal of Genetic Counseling,* 16, 3, 2007, 289–98. For an explanation of stigma communication see: Rachel A. Smith, 'Language of the Lost: An Explication of Stigma Communication', *Communication Theory,* 17, 2007, 462–65; Rachel A. Smith, 'Stigma, Communication, and Health' in *The Routledge Handbook of Health Communication*, 2nd edition, edited by Nussbaum, Jon. F., Roxanne Parrott, and Teresa L. Thompson, London: Routledge, 2011, pp. 455–68.

[434] Woods, 'The Limits of Narrative', p. 74.

narrative and a critique of prominent theoretical ideas in the field – biographical disruption, narrative reconstruction, and Frank's typologies of illness narrative – establish the landscape where this work is situated. Confirming Frank's observation that stories rely on a limited set of narrative resources to articulate experience, I have found that biographical accounts of illness – with their emphasis on linearity, patient autonomy, causality, and an enduring patient identity – to be pervasive.[435] I have experienced the idealisation of Frank's quest narrative in my review of the field of patient narrative and as a participant in patient narrative training with *Patient Voices,* which advocates that a good story must include: point of view, dramatic question, emotional content, opposition, acceptance and transformation, economy of words and images, and attention to pace. I do not wish to trivialise patients' narratives exemplifying these more conventional and traditional forms nor imply that they are necessarily inauthentic;[436] I have argued that experience of genetic medicine poses specific challenges to narration with existing models. These challenges are: living with the risk of an event; causality and the tendency to posit genes as casual factors in biographical accounts of illness at the expense of other relations; chance and its impact on causal relations; indeterminacy; closure and transformation. A consideration of examples of narratives confirmed Kerr's assertion that biographical illness narratives privilege genes as causal factors,[437] neglecting 'the myriad relations that shape how people come to articulate their experience of disease'.[438] I found the methods used to explore patient narrative to be restrictive in their potential meaning and possible forms.[439]

Art practice has offered me a means of extending beyond the formulaic structures commonly seen in patient narratives to explore new ways of narrating experience of genetic medicine. The process of developing appropriate methods for the exploration

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[435] Frank, 'Practicing Dialogical Narrative Analysis', p. 40.

[436] Shapiro, 'Illness Narratives', p. 68.

[437] Kerr, *Genetics and Society*, p. 9.

[438] Ibid.

[439] Waddington and Willis, 'Introduction: Rethinking Illness Narratives', p. iv–v <http://www.literatureandscience.org/wp-content/uploads/2013/09/JLS-6.1-Complete-Issue.pdf> [accessed 28 June 2107].

and articulation of my experience of the CDH1 genetic mutation has both driven and shaped this work. As my understanding of art as research evolved, so too did my methods and their application. In preliminary studies, I did not fully engage with the idea or strategy of actively researching through making. I worked passively, citing intuition as causative without being able to identify and articulate what I intended to explore in making. I have learnt to approach and reflect on my making with an awareness of the decisions I am making as choices with implications, with consequences. I became attentive to what making (and not just the finished work) helps me understand. My decision to conduct close readings of Jean-Luc Godard's *Passion* and *Scénario du film 'Passion',* and Dora García's *The Joycean Society* was made partly in response to these insights. Limiting my detailed readings to these three works opens up possibilities for further looking and learning, for myself and for other patients exploring their experiences. This would not have been possible had I attempted an exhaustive or comprehensive review of narrative works. Focusing on these three works, rather than the wide range of works that might be expected, ensured that I looked outside the world of illness and patient narrative for tools that I could bring back into that field, expanding the 'commonly shared stock of narrative resources that are available to represent what become people's experiences'.[440] By retaining the focus on narrative, I have not felt compromised looking to works outside illness for narrative tools. Indeed, time spent attending to works that do not address illness has provided vital periods of respite and reinvigoration – four years is a long time to concentrate on illness.

I first discovered *Passion* because of a series of coincidences, confounded by my being ill, that led me to watch *Passion* on the first day of my Ph.D.. Through a process akin to Joan Didion's magical thinking, I placed great significance on *Passion's* 'day one' position in my Ph.D. lifecycle. In my diary entry of that day, I write: 'It's as though it makes you happy. Why must there always be a story.' As I came to know the field of patient narratives, I identified overwhelmingly with *Passion's* character Jerzy, who questions why there has to be a story. Interested in the construction of narrative, I was

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[440] Frank, 'Practicing Dialogical Narrative Analysis', p. 40.

further enthused to find *Scénario du film 'Passion'* – a self-reflexive work, where Godard reflects on his methods of scripting *Passion*. I watched García's *The Joycean Society* having been advised to do so by Dr Sharon Kivland, my Director of Studies. I related instantly to the work, its relation to the quest and the literary. With each viewing, I found new meanings. Through these close readings, I have developed methods of looking that would not have been possible had I considered a greater number of works. I employ close looking when making work, making *Future Perfect,* for example, I noticed little details, which I photographed in close-up – the close-up of hair and the photograph of the water that appears next to it. I write about how I experience this close looking in *Testing, Testing: Testing, Memories, and Notes* in my description of the time I spent waiting outside the hospital for an appointment with the HDGC pathologist in Porto on my quest. In addition, I have developed my understanding of the mechanics of film in a way that would have been difficult with a less focussed and narrow way of looking. An immersion in related film theory has lent a philosophical and theoretical level to my understanding, developing my vocabulary of film theory and practice. I have related this to my making, expanding my methods of production to address patient narrative.

The case studies have offered specific insights for the research enquiry, creative practice, and thinking about narrative form and function. Readings of Godard's *Passion*, about which Harcourt writes is 'full of stories but with no plot to thicken',[441] have deepened my thinking about how wholeness of narrative plot can be foregone by detail, limiting and obfuscating a linear understanding. In *Untitled 2014,* the textual and visual narrative fragments on each index card carry equal significance, democratising the events of its narrative. By not differentiating events as constituent of or supplementary to narrative (as is characteristic of emplotment), the uniform significance given to each fragment resists cause and effect causality. Further exploring the distinction between constitutive and supplementary narrative events and the implication of causal relations between events, *Emma Frances O'Connor,* following Godard's *Passion,* combines big stories and small stories, giving equal importance to all.

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[441] Harcourt, 'Calculated Approximations of Probabilities', 1999, p. 12.

Future Perfect is informed by the ending of Godard's *Passion,* which is also an opening, as the characters move on to new beginnings. García's *The Joycean Society* was also instructive: while the film ends, it is not the end of the readers, the text or the reading sessions. *Future Perfect,* as a maquette for a book about the film that I could not make, and *The Document,* a book containing a script for a scene in a film, offer an approach to closure that might be seen as an alternative to conventional patient narratives that through closure 'misrepresent the fundamental indeterminacy of life'.[442] Following *The Joycean Society,* which helped me understand how narrative does not have to make sense to be enjoyable or endured,[443] in *Future Perfect* there is no transformative or happy or sad ending – a critique of master narratives as fictions to make something bearable. *Untitled 2014,* with its non-linear narrative and openness to multiple readings without a predefined telos, lends itself to a reading akin to the readers' in García's *The Joycean Society* close reading of *Finnegans Wake,* as does *A Reading,* which in light of the text's difficulty, introduces the narratee or viewer to a closer reading or viewing.

Godard's use of sound-image dislocation in *Passion* informs *A Conversation: Patient, Artist, Researcher,* where sound-image dislocation between the screen recording of the construction of the scripted interview is out of synchronisation with the audio recording of the same scripted interview. *Passion* gave me new insights about how this narrative technique could be used – as noise or to explore speech not 'as highly individual and locatable' but intersubjectively, *between* a speaker and listener.'[444] As I refuse to characterise or separate roles of patient, artist, and researcher, the viewer has difficulty locating a narrator, which has no source. As in *Passion*, sound-image dislocation, while retaining a sense of shared community, makes it sometimes impossible to attribute dialogue in *A Conversation: Patient, Artist, Researcher* to individual characters. Instances of sound-image dislocation frustrate the viewer, challenging expectations of

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[442] Jurecic, *Illness as Narrative,* p. 38.

[443] See page 134 of this thesis.

[444] Harun Farocki and Kaja Silverman, 'To love to Work and to Work to Love – A Conversation about "Passion"', *Discourse,* 15, 3, 1993, 57–75, pp. 58–9.

clarity and linearity in narrative and research. When I read *A Reading* for an audience, I think about the role of the narratee and their tolerance for what I understand is received as noise. Indeed, Godard's use of noise to obscure and simultaneously communicate reminds me of genetic mutations and the mutated transcript in *A Reading*. The transcript might be described as a textual form of montage: the process of transcription – and the mutation of the spoken conversation – attempts to create a readable and believable, alternative reality. But perhaps it is better viewed as a textual collage, whose brutal cutting disregards this *telos*. As in Godard's *Passion*, the narrator and the narratee of *A Reading* are released from conventional sequential and linear plot (which I have argued can be unhealthy and oppressive for the patient of genetic medicine), leaving open multiple possible readings. Instances of sound-image dislocation in *ST298:402* at times create noise yet at others – the *Semana Santa* parade music in combination with the fish swimming, for example – use filmic conventions to imbue the images with new meaning, as the fish become a funeral parade. Aimée Israel-Pelletier interprets montage ('extreme montage') in *Passion* as 'a series of lengthy fragments of significant events and experiences pulled together by images, words and music in montages that evoke a unified vision of events and experiences – a narrative not so much obscure as irreducible'.[445] Working on *ST298:402* alongside my reading in film theory, I developed an understanding of how narrative and filmic conventions can make meaning.

The script is a concern common to *Passion, Scénario du film 'Passion', The Joycean Society,* and my art practice. In *A Reading* my original conversation with the geneticist was unscripted yet the transcript reading is only a script, lacking any direction division or indication of separate reading parts. Interested in working with chance and risk – of *being with* chance and risk –, I insisted that my father and me read the transcript without rehearsal to see what happened. Despite my refusing a rehearsal, when we read, we divided the text spontaneously and fluently, using recognisable intonation patterns to read meaning into the nonsensical words and phrases; to read *as if* it makes sense. It became a type of communication, meaningless yet with much meaning. In my video works, I use blur as a strategy for addressing indeterminacy. In a seminar discussion

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[445] Aimée Israel-Pelletier, 'Godard, Rohmer, and Rancière's "Phrase Image"', *SubStance*, 108, 34, 3, 2005, 62–78, p. 36.

about *A Reading* with my peers, the idea of textual blur – as a mist or veil – surfaced. It seems that this blur arises between the meaning implied by the voice's intonation and the lack of meaning in the words. The use of intonation imposes a kind of meaning on the transcript. By exploring meaning and its resistance, *A Reading* intervenes with and disrupts the idea – commonly seen in patient narrative – that we have to have meaning. Watching *The Joycean Society* I thought more about communal reading, its relation to meaning making and healing. The transcript – a difficult text – enables the exploration of multiple meanings, for the reader and the viewer. *The Document* also explores meaning, healing, and reading through a conversation that is transcribed, edited, and presented in a book as a script for a scene in a film.

García's *The Joycean Society* explores sound-text-body in relation to narrative. *A Conversation: Patient, Artist, Researcher* dissects the material of narration – it is a taking apart of sound, text, person. The presentation of multiple bodies (me, voice, and text) challenges the wholeness of narrative, the subject, and medicine. Following *Scénario*, *A Conversation: Patient, Artist, Researcher* reveals the construction of my patient narrative in the *Independent* newspaper and the construction of *A Conversation: Patient, Artist, Researcher* itself. Like *Scénario*, it is arranged spatially to explore the gathering of information from multiple perspectives and my occupation of multiple positions in my autoethnographic work.

Deleuze's writing about Godard and the 'method of BETWEEN'[446] has enhanced my understanding of montage in *ST298:402,* enabling an exploration and articulation of the third, indeterminate space I find myself occupying, between illness and health: my *living in* prognosis, my *being with* risk. With montage, I explore not only travelling between illness and health, but also being in-between the two categories, which at once seemed more fluid. In *Future Perfect* I explore the spacing between images, words, and the page, following my learning through *Passion*, as an interstice that – in light of its spaciousness and absence of plot – opens up potential for new meanings. The

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[446] Gilles Deleuze, *Cinema 2, The Time-Image,* translated by Hugh Tomlinson and Robert Galeta, London: The Athlone Press, 1989, p. 180 [*Cinema 2, L'Image-Temps,* Paris: Les Éditions de Minuit, 1985].

composition of *Future Perfect* is, as M. Bonnel says in *Passion,*[447] full of holes. Absence of plot enables the spaces between the images to function as interstices, opening up a third space for contemplation. It is in this third space that I explore the liminal space between illness and health – the space I occupy as a patient of genetic medicine. *Future Perfect* does not resolve this being inbetween – it cannot, in light of my experience. The use of montage and the absence of plot in *Fin* is also informed by my readings of *Passion*.

Making *Silence for the Convalescing,* I was thinking about *Passion* and Benjamin's question of how the cameraman compares with the painter.[448] Godard says that *Passion* exists somewhere between the stomach and the lungs. With the inclusion of X-ray footage, I explore ways of capturing and looking. Addressing how the hospital cameras look through the surface of my body to new surfaces, *Silence for the Convalescing* explores how surface might be preserved, distorted, transgressed, seen through, and created with technology.

Questioning why Godard made *Scénario,* I reflect on my making *S:ST298:402,* wondering if his motivation bore any relation to mine – an attempt to fix narrative: *S:ST298:402* was intended as a thread that might function to sew the images in *ST298:402* together.

My close readings of *Passion* and related theoretical texts gave me new insights into how I might use movement and stillness in my art practice. In putting together *Future Perfect*, I thought about Manubens' suggestion that lingering in stillness, achieved in *Passion* by the camera's movement around stilled action, subverts the normative

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[447] Ibid.

[448] Walter Benjamin, 'The Work of Art in the Ages of Mechanical Reproduction', in *Illuminations*, London: Pimlico, 1999, p. 226. Cited in Anna Manubens, 'Godard's Lingering Camera From *Le Mépris* to *Passion* and Back', *Critical Quarterly,* 53, 2011, 208–24 (Issue Supplement: *Godard's Contempt, Essays from the London Consortium,* edited by Colin MacCabe and Laura Mulvey) p. 212.

narrative progression of film.[449] I spent most of my days in Porto moving – walking and travelling – yet my experience was of stasis. Photographs taken with my Pentax film camera (see page 90) comprise the images in *Future Perfect*. Quite like Godard's use of voice-over, as a soothing commentary on the film's action for contemplation, text in *Future Perfect* is meant for contemplation.[450] Broadening the contours of how a patient narrative might be experienced, I wanted to encourage the viewer to linger in this work, just as I lingered in Portugal, contemplating what I saw looking outwards and inwards at my experience of genetic medicine. The sequence of images in *Future Perfect*, like those in *Passion,* do not have the amnesiac effect on the viewer, a term used by Víctor Erice and discussed on pages 143 and 144.

Adelante Series II was developed while thinking about place in *Passion,* which brought to my attention the places that are marked for me as a patient – home, hospital, waiting rooms, doctors' rooms, hospital wards, theatres, and toilets. I thought about how I traverse between these spaces. Emotionally, moving between these spaces is almost always extreme and in flux. This manifests in bodily movement, expression, and my voice. I explored Godard's use of pace, and rhythm, and movement, *being in* the world and the everyday as opposed to the heroic. I was cognizant of Pierre Bourdieu's concept of *habitus* – reflecting on my experiences of moving between significant places (and the changes in my movement through these spaces) with this lens.

In *Ars Longa, Vita Brevis* I video myself fleetingly in reflective surfaces. I was thinking about how Godard employs staging and framing as ways to explore and analyse what it is to be a patient of genetics, with the stage conceived as a potential critique of a genetic patient's exploration of her/his position and status as patient.

While Waiting will employ the film techniques that I learnt through repeatedly watching *The Joycean Society*. Close-up video and sound recordings in real time will observe

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[449] Laura Mulvey, 'The Death Drive: Narrative Movement Stilled', *Death 24x a Second*, London: Reaktion, 2006, p. 69. Cited in Anna Manubens, 'Godard's Lingering Camera From *Le Mépris* to *Passion* and Back', *Critical Quarterly*, 53, 2011, 208–24, p. 215.

[450] Please see discussion of Godard's use of voice-over on page 113.

conversations between others and me about waiting for replies. A handheld camera will capture my movements (not rehearsed performances) through daily activity lending a rhythm to the work; my chasing after signs and consequent magical reasoning will constitute slight changes in pace. The film might be read as a coming-to-terms with a not knowing if there will ever be a reply, and in so doing, like the reading of Joyce, it develops its own momentum and new meanings, all the time resisting closure.

Thus, I have developed my autoethnographic art practice, narrating my experience of genetic medicine in multiple forms – text, performance, installation, still and moving image. Departing from the conception of autoethnography as text-based, my autoethnographic methods are grounded in art practice. To demonstrate that the art practice is autoethnographic, I refer back to my body of art practice to consider the specific insights delivered by the art practice in making connections between individual patient experience of genetic medicine and wider culture/society. Although the following discussion demonstrates that art practice is autoethnographic, considered together, the body of art practice produced in *Re-imagining Patient Narrative* alongside the textual academic analysis are understood as an autoethnography.

Untitled 2014 shows how my own experience interacts with broader culture as I introduce Sean Swarner, a young American in his thirties, voted one of the eight most inspirational people of all time. Sean was diagnosed with two forms of cancer and given just weeks to live. A climber, he went on to conquer Everest and keeps a travel blog. It was while researching medical laboratories in Portugal that I discovered Sean through this participation in 'Dia da Coragem' at the Instituto Medicina Molecular at Santa Maria Hospital in Lisboa. I was drawn to Sean because of his archetypal heroic character. On other index cards, I self-reflexively write about 'craving the order I was questioning', contemplating the expected delivery mechanisms, and 'The Grand Illusion' – that there really is a beginning, middle, and end. *Traces, as Evidence That Conversation Happens* includes an excerpt from my quest notebook, where under the heading Joseph Campbell, I write: 'the path of a hero is well trodden, you don't have to think'. Questioning why the hero remains, I cite Campbell: 'It's what's worth writing about' and I ask: 'And what's worth doing?' *A Conversation: Patient, Artist,* *Researcher* further explores how my personal experience of genetic medicine intersects with institutional and cultural biases towards certain narrative structures through its analysis of a 'real life' construction of one of my patient narratives, written for the *Independent* newspaper. In so doing, it reflects on narrative as commodity. *S:ST298:402* reveals my thinking at the time about whether experiences of genetic medicine can be corralled into a patient narrative and my consideration of the cultural expectations of so doing. It features part of a script for a scene that takes place inside a train carriage. One of the characters is thinking about her film and wants to give readers something to grasp onto. It reads: 'She wonders whether there must always be a story, and settles on the illusion of story.' Significantly the word 'settle' refers to an act akin to one of surrender. I recall – with trepidation – Frank's claim that rather than surrendering personal narrative to the biomedical terms and voices imposed on them, patients now have the narrative resources to reclaim control over the telling of illness.[451]

ST298:402 explores my experience of genetic diagnosis and preventative surgery, which runs contrary to stabilising conventional patient narratives, where the agentic patient (no longer the subject) narrates events. Using myself as an instrument of research, I have explored the quest narrative structure, which with its insistence on transformation is often referred to as the ideal patient narrative. Having begun a quest, which took me to Portugal, to locate my stomach, I investigated emplotment and the relations between experience and narrative. Editing *ST298:402,* I was torn between constructing a coherent narrative and resisting this desire – cutting and combining my footage with no over-arching narrative to rule my decision-making, articulating a non-plot that would better reflect my experience of being adrift with no agency to corral the events that were unfolding in my life. During the making process, I experienced the lure of the quest narrative and disappointment that it did not fit my experiences. This significant insight is discussed and analysed textually in my thesis, demonstrating that autoethnographic art practice delivers insights about the culturally sanctioned quest narrative and its relevance for patients of genetic of genetic medicine.

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[451] Frank, *The Wounded Storyteller,* p. 6.

In *Future Perfect* an image of a reflection captures an advert featuring a man and woman stood together, their hands held on her stomach, as she is pregnant. The couple do not appear to scale in the image, which they dominate. They are reflected again in the left of the image, merging with a street scene. In the centre of the image, I am just made out, looking up at the couple. It is perhaps here, by drawing attention to an individual located within wider cultural and societal narratives around family that *Future Perfect* most explicitly connects my individual experience of genetic medicine and broader culture and society. As a carrier of the CDH1 genetic mutation, I must make decisions around family planning since there is a 50% chance that any child of mine will also carry the mutation. I paid attention to colour when editing images: domino-like, I used colour to hold sequences of images together in *Future Perfect*. I also used cultural understandings about colour to reflect feelings – the first sequence of images are blue, emphasised by the accompanying text which simple reads: 'Blue'. This suggests how autoethnographic art practice can employ cultural understandings in its telling. Midway through *Future Perfect*, a series of religious images recount my detour to Santiago de Compostella in Spain. I decided to go on a train to Santiago de Compostella in part to escape and in part to take some ownership of my narrative. I explored my quest to trace the journey of my stomach and its telling in relation to cultural narratives of pilgrimage.

Untitled 2014 connects my experience of genetic medicine with wider stories about research and data. Settings, informed by Internet research, detail the conditions of medical genetic laboratories; medical research, specific to the E-Cadherin gene emphasising the neglect of literature about families with the E-Cadherin, is recounted. The title of *ST298:402* is a particular instance of where my autoethnographic art practice connects my individual patient experience of genetic medicine with broader culture and society, as it explores naming and referring as aspects of medical discourse. Using numbers to identify patients is common practice in medical research and raises ethical issues around naming, withholding, and anonymity. My re-appropriation of my patient number raises questions as to my motives: an effort to take control, an attempt to use the tools of anonymity to fight against anonymity, or a scar bravely worn. *A Conversation: Patient, Artist, Researcher* takes the form of an interview, connecting individual patient experience of genetic medicine and the use of interviews to collect patient narratives as data in qualitative research, inviting dialogue about notions of researcher and researched. Arranged spatially, *A Conversation: Patient, Artist, Researcher* weaves my individual experience of genetic medicine together with broader understanding of research and triangulation to gather information from multiple perspectives. *Emma Frances O'Connor* situates my personal experience of genetic medicine alongside its research context, as I reflect on prominent ideas in the field of patient narrative in the work. As autobiography is not permitted on Wikipedia, *Emma Frances O'Connor* invites dialogue about the value of ones own story and autoethnographic practices, exploring audience expectations regarding the authority of the text. When made a live page on Wikipedia as part of my participation in *In Dialogue 2014,* it was instantly taken down due to Wikipedia's stance on autobiography. Fulfilling a requirement of its publication, *Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia – A Chapter* frames the original work with a traditionally written academic text, adding further context and interpretation. *Muito Frágil: A Self-Contract* invites reflection on the position of the researcher in autoethnography. Locating *Muito Frágil: A Self-Contract* within wider discourse around ethics in research practice, connects my personal experience of doing research as a patient of genetic medicine with wider research culture.

My grandfather's mode of storytelling in *SEAMUS & ST298:402 – In Conversation* situates his own story within broader socio-cultural and economic narratives. He says, for example, that 1921, the year he was born, was also the year that the Irish Free State was declared. In *S:ST298:402* fragments of my experience of genetic medicine connect with other fragments relating to broader culture and society – a quote from Carlos Fuentes about memory, barely visible hospital letters, email exchanges, a postmark from Portugal, a figure of an example gastrectomy specimen processed for pathology, a city map of Lisbon, and a table that summarises research participants in 'The Impact of Prophylactic Total Gastrectomy on Health Related Quality of Life: A

Prospective Cohort Study'.[452] *Ars Longa, Vita Brevis* moves between first and third person viewpoints, facilitating a way of attending to my individual position as located in wider culture and society. Connecting my individual experience of genetic medicine with institutional languages situates *Adelante Series II* as a commentary and critique on the embodied relations of power and privilege in institutional settings. Reflections on the crit that followed exhibition of *Adelante Series II* (in my text *Traces, as Evidence That Conversation Happens*) relate also to Bourdieu's *habitus,* illuminating social, cultural, and institutional dispositions to speak in certain ways.

The title of *Future Perfect* refers to the future perfect tense and the role it plays in my experience of genetic medicine as I am encouraged by medical professionals to employ the future perfect (not so perfect) in my decision-making – b*y the time I am 40,* I + will + have + past participle of main verb… Insights are delivered through connecting my personal experience with broader medical discourse around decision-making.

Re-imagining Patient Narrative contributes a body of art practice that addresses patient narrative which, through its exploration of experience of genetic medicine in novel ways (through film, text, photography, installation, and performance – as evidenced in the accompanying *Pé de Grue* volume), expands the array of narrative resources used to voice patient experiences of genetic medicine. In looking beyond what Waddington and Willis describe as the paucity of methods commonly used to explore patient narrative, I offer this work, its potential new meanings and forms, to the field of patient narrative.[453]

An elaboration of the claim that art can critique and have an impact on the expectation and form of the patient narrative, as promoted and experienced in medical profession

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[452] Elizabeth Worster, Xinxue Liu, Susan Richardson, Richard H. Hardwick, Sarah Dwerryhouse, Carlos Caldas, Rebecca Fitzgerald, 'The Impact of Prophylactic Total Gastrectomy on Health Related Quality of Life: A Prospective Cohort Study', *Annals of Surgery*, 260, 1, 2014, p. 87–93.

[453] Waddington and Willis, 'Introduction: Rethinking Illness Narratives', p. iv–v <http://www.literatureandscience.org/wp-content/uploads/2013/09/JLS-6.1-Complete-Issue.pdf> [accessed 28 June 2107].

contexts, ensues through a discussion of my own work to reflect on exactly what art might offer in a clinical context that opens up medical discourse and patient experience.

My work employs the fragment, which by limiting and obfuscating a linear understanding challenges the expectation of wholeness of narrative plot in patient narrative. The book format employed in *S:ST298:402* has facilitated my exploration of fragments of my patient experience and indeed my self, which when presented together in the book retain the fragment while narrating my story. *Untitled 2014* adopts the use of index cards by screenwriters as plot creation tools in the early stages of writing. Just as viewers of *Untitled 2014* are invited to flick through, re-order, and remove (purchase) the index cards, a screenwriter might categorise, re-order, and rearrange her/his index cards, allowing for the non-linear visualisation of a story, before proceeding to the next stage in the writing process. In resisting this ‘next step’ in plot creation, each index card in *Untitled 2014* remains a fragment, not clearly part of a larger, linear narrative. Containing the index card in a clear plastic box, further explores containment and the relation of narrative to risk.[454]

The presentation of fragments of my journey to find my stomach with still photographic images in *Future Perfect* reveals spaces in my recounting. I explore the spacing between images, words, and the page, following my learning through *Passion*, as an interstice that – in light of its spaciousness and absence of plot – opens up potential for new meanings, enabling the spaces between the images to function as interstices, opening up a third space for contemplation. It is in this third space that I explore the liminal space between illness and health – the space I occupy as a patient of genetic medicine. *Future Perfect* does not resolve this being inbetween – it cannot, in light of my experience. The text accompanying the still photographs in *Future Perfect* is meant for contemplation to encourage a sense of lingering in stillness,

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454 Jurecic, *Illness as Narrative*, p.33.

subverting the normative narrative progression of film.[455] Broadening the contours of how a patient narrative might be experienced, I wanted to encourage the viewer to linger in this work, just as I lingered in Portugal, contemplating what I saw looking outwards and inwards at my experience of genetic medicine.

A Conversation: Patient, Artist, Researcher dissects the material of narration – sound, text, and person. Through its presentation of multiple bodies (me, voice, and text) *A Conversation: Patient, Artist, Researcher* challenges the wholeness of narrative, the subject, and medicine.

Untitled 2014 explores patient identity through narrative. The removal of the index cards, like the removal of my stomach, suggests an approach to narrative that offers an alternative model to the one referred to by Woods, when she writes that narrative as a mode of self-expression promotes a particular model of self:

> As an agentic, authentic, autonomous storyteller; as somebody with a unique insight into an essentially private and emotionally rich inner world; as someone who possesses a drive for storytelling, and whose stories reflect and reaffirm a sense of enduring, individual identity.[456]

ST298:402 explores my identity as a patient through the filming of myself in surfaces with different degrees of opacity and reflectivity. In *Ars Longa, Vita Brevis* I video myself fleetingly in reflective surfaces. I was thinking about how Godard employs staging and framing as ways to explore and analyse what it is to be a patient of genetics, with the stage conceived as a potential critique of a genetic patient's exploration of her/his position and status as patient. Employing film techniques to explore 'off-screen/offstage' relations in the creation of a genetic patient narrative, I explore how I might reveal and obscure myself: a play of showing, hiding, looking at

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[455] Laura Mulvey, 'The Death Drive: Narrative Movement Stilled', *Death 24x a Second*, London: Reaktion, 2006, p. 69. Cited in Anna Manubens, 'Godard's Lingering Camera From *Le Mépris* to *Passion* and Back', *Critical Quarterly*, 53, 2011, 208–24, p. 215.

[456] Woods, 'The Limits of Narrative', p. 74.

and looking through. The ‘off-screen/offstage’ relation helps me see how my work generates knowledge: How I reveal and obscure myself (my self) through the reflections is the problem of patient narrative in miniature. On viewing the reflective footage in *Ars Longa, Vita Brevis*, my peers reported that while they sensed that I was exploring, nothing was given to the viewer – with no point of reference, they felt they were searching for something to latch onto. Viewers describe *ST298:402* as having a sensorial quality, relating the feeling of sensing something before knowing – a kind of understanding that occurs retrospectively. This relates to both to Woolf’s writing about an absence of words for embodied experiences of illness and how the story of body lacks plot, and to Frank’s writing, that ‘the meaning of the journey emerges recursively: the journey is taken in order to find out what sort of journey one has been taking.[457] *ST298:402* offers an alternative approach that allows for the exploration of patient identity.

Future Perfect further explores my identity as patient (and my position in this research) through reflective surfaces with various degrees of opacity that capture me outside looking in, and inside looking out; exterior and interior worlds elide as images touch. An image of the heavy vertical lines of a trellis appears prisonlike and I think about Adam Phillips’ use of ‘sepulchral’ to describe biography as entrapment (see page 67). My position in the work is further explored in *Future Perfect* when I refer to myself in both the first and third person. In *Silence for the Convalescing*, I am the filmmaker looking out into the world; the subject, as someone else has taken the x-ray and gone inside me; and the filmmaker looking into my own body. There is movement from where I position myself as I replace this with the viewer. This movement is physical as the camera is used to look in and out – an inversion mirrored in the inverted reflection of the water in the Moorish Palace (a further surface that might be preserved, distorted, transgressed, seen through, and created with technology). The – sometimes dynamic – switch in position between me as subject and object can also be seen in my textual work, as I switch between the first and third person (see *S:ST298:402*, for example). This multiplicity of different points of view, voices, and

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[457] Frank, *The Wounded Storyteller*, p.117.

positions disrupts conventional notions of character within narration – particularly the role of the patient in the patient narrative.

Through its refusal to characterise or separate the roles of patient, artist, and researcher, *A Conversation: Patient, Artist, Researcher* frustrates the viewer who has difficulty locating a narrator, which has no source: A lack of characterisation leaves the viewer uncertain about who is speaking. Instances of sound-image dislocation in *A Conversation: Patient, Artist, Researcher* generate noise, further frustrating the viewer, challenging expectations of clarity and linearity in narrative and research. The narratives I employ in *Adelante Series II* are disruptive because, like a genetic diagnosis, they promise and deny direction. While viewers may take a ticket from the dispenser and wait for their number to appear, it is not clear what, if anything, will happen; the coloured lines on the floor appear to offer direction, yet seem to lead nowhere.

The video element of *Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia* shows the construction of the entry: the processes of its being edited, authored, co-authored, constructed, and co-constructed. In so doing, *Emma Frances O'Connor* invites critique and dialogue on its value and formation, offering an alternative narrative to the ubiquitous and culturally expected form of patient narrative. The script in *A Document* relays a conversation about how – and for what purpose – a patient narrative might be constructed and read, troubling the notion of an ideal patient narrative and reader thereof. I allude to the narrative under-construction in *Future Perfect* and its deferral through a series of images of hospitals accompanied by text that reads: 'a whistle-stop tour', 'a reconnaissance', and 'under-construction'. *A Conversation: Patient, Artist, Researcher* reveals the construction of my patient narrative in the *Independent* newspaper and the construction of *A Conversation: Patient, Artist, Researcher* itself. A refusal to conceal the multiple ways in which narratives are constructed may be valuable for other patients of genetic medicine because by exposing the mechanics of patient narrative, patients would see how they are constructed and would not be duped by the conventions of happy endings nor feel inadequate by not playing the hero. By revealing the construction of narrative, art practice facilitates thinking about patient narrative in more complex ways – a strategy that might be employed usefully in medical contexts to open up the medical discourse and the patient experience. As such, this strategy responds to Ulhas Macneil's calls for work that:

> Defie[s] easy understanding and resists being pressed into the service of medicine and other health professions for educational purposes by opening up topics for exploration and discussion without providing unitary explanatory frameworks.[458]

Fin does not offer ending nor closure to the viewer, who will never experience the work as complete. In a clinical context, this invites dialogue about the patient experience and the expectation that it can be sufficiently captured in a conventional patient narrative, troubling its use as data. In *Untitled 2014* the index cards – the material of research and institutions – draw together research, institutional languages, and narrative methods. The index card, a bureaucratic research tool, records. As a data method, the use of index cards – like the use of patient narratives as data – is both complex and limited. *Untitled 2014* presents data without answers, offering a further way in which art might disrupt practices that allow research reports to draw conclusions and come to an end by confusing a stability of narrative resources with the 'finalisation of storytellers themselves.'[459] *Emma Frances O'Connor* addresses the challenge of narrating living with risk and its relation to closure. The work ends: 'All this before I even begin to tell my story' – a final resolution is not offered, leaving open future possibilities for further revision and multiple restructurings.

Exploring the distinction between constitutive and supplementary narrative events and the implication of causal relations between events, *Emma Frances O'Connor*, combines big stories and small stories, giving equal importance to all. Although *Emma Frances O'Connor* explores family heritage and lineage, it challenges the

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[458] Paul Ulhas Macneill, 'The Arts and Medicine: A Challenging Relationship', *Medical Humanities,* 37, 2011, 85–90, p. 85.

[459] Frank, 'Practicing Dialogical Narrative Analysis', p. 37.

expectation that in biographical illness narratives, genes will be posited as causal factors. However, it is possible that using the form of a Wikipedia entry is too removed from medial profession contexts to have an impact here. *Ars Longa, Vita Brevis* explores the creation of a biographical patient narrative with transmedia, using video to showcase a slide projection of images from my childhood. Genetic illness challenges the view, implied in biographical accounts of illness,[460] that there is an easily isolated patient identity, raising questions not only in regard to patient identity, but also to concepts of illness as biographical disruption. It is not the case that I was ill and that now I am well. Indeed, it is almost the reverse (since I was well before electing to undergo prophylactic surgery), with fluctuations between states of wellness and illness.

SEAMUS & ST298:402 – In Conversation narrates patient experience *via* a conversation that occurs between generations in one family, offering a way of addressing family lineage in genetic mutations and the effect of genetic illness on family members. The inclusion of family in the patient narrative challenges conventions of individual patient narrative. *S:ST298:402* includes two pieces; one written by my father, the other by my mother. Art practice offers a way of addressing family lineage in genetic mutations and the effect of genetic illness on family members. In *ST298:402* I write about the scripted delivery of information that constituted receiving my genetic diagnosis and this is further explored in *A Reading*. A genetic diagnosis writes a life history from (or better, long before) its very beginning not the end, and in reverse. Through using the transcript, *A Reading* explores ideas and feelings around the reading of a script, a genetic script, and genetic mutations, through a mutating text. The approach of obfuscating and troubling script in *A Reading* is an exploration of and a reaction to being an embodiment of a genetic script. In so doing, *A Reading* invites dialogue about how a genetic diagnosis might be received, experienced, and understood. *The Document* explores the script as something that must be interpreted, acknowledging Woodward's warning (see page

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[460] Woods, 'The Limits of Narrative', p. 74.

53) against viewing genomes as a script without understanding that the numbers refer to general probabilities that must be interpreted, not to facts.[461]

Reflective surfaces pull me in and reject me, and can make me see and think about myself in different ways. I remember my mum taking me to the bathroom for the first time post-gastrecomy in hospital and warning me about what I might see in the mirror. (I do not remember what I saw.) At the end of *Ars Longa, Vita Brevis*, I video myself in the mirror of a hospital changing room cupboard, dressing after an MRI scan. It was a traumatic experience and my body is marked and blotchy. This last scene marks a departure from my previous work as I figure in it, not fleetingly but blatantly and uncomfortably as a patient. The Return of the Patient. Something that had previously been missing as I realise much of my art practice before my Ph.D. had functioned as a means of escape. In *Ars Longa, Vita Brevis* the inclusion of me as patient sets up and dismantles the apparent binary of patient and healthy person. Peers report that this marks the most powerful turn around for the audience contrasting with the first part, which they say feels like a home movie. When suddenly I enter the film as another, the audience have to make sense of it in a particular way that feels uncomfortable.

Future Perfect addresses some of my more difficult and unstable experiences post-gastrectomy. I explore ways to articulate my misuse of painkillers with images of me in a white robe organising pills on the white sheets of a bed, a colour associated with institutions of rehabilitation. Yet this is not explicit and there is hiding behind words referring to an actress in a pharmacy.[462] Offering this in a clinical context opens up the medical discourse and patient experience.

Risk and chance are central to my experience of genetic medicine, significantly differentiating this experience from that of an illness. *A Reading,* through not attempting to narrativise chance and risk by relinquishing control and leaving the

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[461] Woodward, Kathleen, 'Statistical Panic', *Differences: A Journal of Feminist Cultural Studies*, 11, 1999, 177–203. Cited in Jurecic, *Illness as Narrative,* p. 28.

[462] *Muito Frágil: A Self-Contract* addresses more explicitly some of these issues.

transcription process to chance, ensures that Jurecic's uncontainable remains uncontained.[463]

In *Adelante Series I* the unsteady handheld camera shots of my feet walking to hospital appointments convey a sense of my disorientating journeys to and through hospitals. Curious about where the energy and agency comes from in the moment of stepping, I explore what makes me walk onwards when I feel like pulling back. The word *Adelante* is a Spanish word meaning forward, onward, to go ahead in place or in time. Throughout the work, non-synchronised sound of the opening of electric hospital doors punctuates the moving images. The lines on the hospital floor and on the roads (broken, institutional lines) are lines used for orientation. In *Adelante Series I* they invite contemplation of multiple possible narratives – about destiny, choice of narrative, and about how narratives might be co-constructed by patients and doctors. The hospital walking footage contrasts with footage taken on my digital SLR camera in landscape format, in which I am also walking, but through the Alcázar of Sevilla. In these shots, there is no synchronised sound, which creates a more dreamlike feeling of disembodiment. *Silence for the Convalescing* employs sound – a tapping noise – which, as a clicking through, signifies moving through time. Its mechanical feel is like an automaton, lending a certain pace to the video that I set. Yet, as in *Adelante Series I,* I explore the relation between momentum or advancement and agency.

As a consequence of the prevalence of dominant and culturally sanctioned patient narrative structures and plotlines, narratees bring with them particular expectations. *A Reading* offers an alternative and different reality to what is expected; a narrative that does not end in meaning, and resists providing a single, unitary, explanatory framework. Thus, as in *The Joycean Society's* readers of *Finnegans Wake,* the narratee or viewer is introduced to a closer reading or viewing. In a clinical context, this has the potential to open up medical discourse and the patient experience.

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[463] Jurecic, *Illness as Narrative,* p.33.

ST298:402 resists transformation: I am not transformed by illness, and *ST298:402* does not frame it as enriching. While acknowledging that patient identity is not hegemonic, *ST298:402* with its relation to my everyday experience of genetic medicine, suggests the 'quest' narrative – with its insistence on transformation and heroic connotations – is a less useful term. My quest narrative has not led me to locate my stomach, which seems to exist off-record, although it appears it did travel to Porto and I suspect that it is now in Leeds. 'Where are the stories of failure?'[464] Jackie Stacey writes that stories not fulfilling heroic cancer narratives are left untold, silenced.[465] McKechnie writes 'not all stories of illness are helpful – or healthy entities – in the world'.[466] In this way, I offer what is not being represented in conventional patient narratives to open up the medical discourse and patient experience. *Muito Frágil: A Self-Contract* explores my experience journeying to find my stomach, 'trying on' the quest narrative. Addressing issues of body weight and body image, painkiller misuse, fatigue, work/life balance, and the difficulties of autoethnographic practice, my narrative is far from heroic, and my illness is not portrayed as enriching. I employ art practice to play with form and genre – that of a patient narrative and a contract (and in *Dear Godard,* and *Dear García,* that of a letter) – to reveal these private and often unspoken experiences, which may also be the experiences of other patients of genetic medicine, opening up medical discourse and the patient experience. In *Future Perfect* there is no transformative or happy or sad ending – a critique of master narratives as fictions to make something bearable. This counters the expectation of transformation (something should be learnt from illness) in patients' narratives and in discourse around genetics, where sociological research foregrounds the transformative properties of genetic technologies on patients (see discussion on page 52).[467] *SEAMUS & ST298:402 – In Conversation* my speaks of a time – just weeks before his wife's diagnosis and only months before her death – when they were holidaying in Norway; he took a photo of his wife, Mod and said 'Maise, you look

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[464] Lisa Diedrich, *Treatments: Language, Politics, and the Culture of Illness,* Minneapolis, MN: University of Minnesota Press, 2007, p. 54. Cited in McKechnie, 'Anxieties of communication', p. 122.

[465] Jackie Stacey, *Teratologies: A Cultural Study of Cancer,* London: Routledge, 1997. Cited in McKechnie, 'Anxieties of communication', p. 122.

[466] McKechnie, 'Anxieties of Communication', p. 122.

[467] Kerr, *Genetics and Society,* p. 6.

different'. What begins a light-hearted history full of spontaneous travel plans, ends when he reaches the time of his wife's early death from stomach cancer and words escape him. There is not a glimmer of triumph or transformation in his telling.

S:ST298:402 includes a speculative film poster – a black and white image of an airport waiting area with planes and my reflection just about visible. The image – which employs the trope of a journey – fills the page and overlaid text reads '*A poster for a film, ST298:402, by Emma O'Connor'*. Framing the work as a poster for a speculative film addresses and circumnavigates the problem of closure, signalling a beginning with the making the film in the future. *The Document* is a book containing a script for a scene in a film, as yet unmade. With *Dear Godard,* and *Dear García,* the viewer does not know if I ever received replies to my letters, or whether Godard and me will ever work together on a film as I propose. As a maquette for a book about the film that I could not make on my quest to trace the journey of my stomach, *Future Perfect* critiques the expectation of closure in patient narrative – which 'misrepresent[s] the fundamental indeterminacy of life'[468]– offering an alternative approach: deferral. Deferral runs through the work in the text accompanying a photograph of my hand writing that reads 'Promising Lists', and a dark, grainy photograph of me in bed with text reads 'Dear Scheherazade', suggesting the use of stories to stay alive. The title *Future Perfect* alludes to this deferral. *Future Perfect* offers an approach to closure that might be seen as an alternative to conventional patient narratives that through closure 'misrepresent the fundamental indeterminacy of life'.[469]

Fin addresses the problem of closure and offers an alternative: tactics for the everyday – I live with the wretchedness, without expectation of a happy ending. I notice that my making used to function as a means of escape and hidden narratives. Now, it is also a practice of *being with*.

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[468] Jurecic, *Illness as Narrative*, p. 38.

[469] Jurecic, *Illness as Narrative*, p. 38.

Conversations between the geneticist and me in *A Reading* furthered my understanding of how art can practically open up medical discourse and patient experience: as a micro intervention, our conversation – as part of my art process – offered up something new to both of our understandings of genetics, opening up medical discourse, and the patient experience. Future conversations with medical professionals took a similar exploratory and conversational form, leading me to use the term 'befriending' to capture the nature of these interactions. New understandings generated by these conversations constitute a somewhat subtle way that my art practice generates new insights in medical profession contexts, by having an impact on the expectation of the patient narrative. Although subtle, this is nonetheless considered: these conversations would take place with influential medical professionals – geneticists, pathologists, and principal researchers – in the field of Hereditary Diffuse Gastric Cancer.

The title *Silence for the Convalescing* is an abstract invitation to the viewer to feel what I felt. There is movement in the viewer/filmmaker communication – thinking inside about the emotional experience that I had, and looking out. The title gives viewers a sense of this. Characters in *The Document* discuss empathy and the role of the narratee.

Key ways that art making in the genetic patient context have challenged patient narrative are explored in detail above but are, in summary:

- Giving equal importance to events of different scale to prevent causality and inference
- Using fragments of information open to interpretation to disallow a transformative conclusion
- Not allowing narratives to have closure so that 'fundamental indeterminacy' is maintained
- Deliberately positing indistinct patient, carer, artist, researcher, narrator roles – multiple bodies that challenge an expectation of a 'whole' narrative
- Refusing characterisation

- Using sound and image to make the narrator unlocatable – between speaker and listener
- Working actively with chance and risk to unsettle the tendency to generate linear and chronological narrative
- Using montage to fragment or blur the space between illness and health
- Using stillness and movement to subvert expected pace of plot movement
- Critically observing and communicating my tendency to seek a narrative and using strategies to confound this.
- Critiquing the ‘future perfect’ language of narrative through disrupting linear narration
- Disrupting how the narrator usually appears by moving between being subject and object – using obscuration, reflection and opacity
- Exposing strategies of conventional narrative formation to give the viewer agency

Contribution to Knowledge

I contend that art practice can critique and have an impact on the expectation and form of the patient narrative of genetic medicine, as promoted and experienced in medical contexts, and this is proposed as a contribution to knowledge. This claim is elaborated through this practice-led research and its discussion – where I reflect on what exactly art might offer in a clinical context that opens up the medical discourse and the patient experience.

My second – methodological – contribution lies in the expansion of autoethnography to include autobiographical art practice to amplify possibilities for insight and new understanding. As it operates as auto-ethnographic enquiry, making connections between individual patient experience of genetic medicine and broader culture and society, this practice-led research delivers knowledge and insights about patient narrative and experience of genetic medicine.

Implications and Further Work

Situating my work in the field of patient narrative, I present my narratives – which extend beyond conventional forms (with their emphasis on linearity, causality, biographical disruption, and transformation) – for consideration as narratives of patient experience of genetic medicine. This contributes to – and has implications for – those literatures attending to the definition of the genre of patient narrative. Woods considers the over-inflation of what constitutes narrative, suggesting that too much is included under the 'narrative umbrella', emphasising that continuity between forms of 'narrative' detracts from analysing the functions and effects of different types narrative.[470] The motivation of Woods to define the boundaries of narrative appears to be the concern that the term 'narrative' will become too inclusive and thus detract from its unique features that allow us to demonstrate its inherent value. Moenandar, citing Donata Meneghelli, points to the necessity of delineating storytelling and narrative from other discourses more loosely associated with communication to ensure that narrative's unique value to theory and practice is maintained, rather than diluted by close imitations.[471]

However, accepting a narrow understanding of what constitutes narrative risks the exclusion, and thus silencing, of certain voices – those that do not fit often-undefined notions of narrative – avoiding what could be a very lively debate. While heeding the warning expounded by Moenandar, Meneghelli, Woods, and others, I propose that it is unhelpful to begin with the assumption that any outward shift of the boundaries of what is accepted as narrative in medicine undermines the value of narrative as a tool to account for patient experience.

The definition of patient narrative does not exist in the world to be discovered; rather, it is invented and a case is made for why it is the most 'fitting'. However, it is not clear to what these definitions must fit if the concepts do not exist *a priori* to their

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470 Brian Hurwitz, Trisha Greenhalgh, and Vieda Skultans (eds), *Narrative Research in Health and Illness,* Oxford: Blackwell, 2004, p. 1. Cited in Woods, 'The Limits of Narrative', p. 74.

471 Donata Meneghelli, *Storie proprio così: Il racconto nell'era della narratività totale*, Milan: Morellini editore, 2013, p. 14. Cited in Moenandar, 'Introduction', in *Stories of Becoming*, pp. vii–viii.

definition. It is more realistic to consider the definitions as 'fitting' to the exemplars that it is felt should be included. The genre needs challenging; it could be fruitful to consider the multiplicity of narrative voices as the foundations on which pre-conceived definitions of narrative might be re-assessed. A consideration of the multiplicity of narrative voices under the 'narrative umbrella' may enrich understanding of narrative, its uses in illness and patient identity, its idiosyncrasies, limits, and indeed, its definition.

Having produced a series of works addressing my experience of genetic medicine, the role that these narratives might play more fully in the clinical field (in addition to the academic field), enabling access to Mishler's 'voice of the life world',[472] can now be considered. I have seen how patients' narratives are being used in the clinical field, in my own experience as a patient, and on *Telling Stories* website, for example, which enables learning through stories about 'real-life genetics'.[473] In positioning my narratives in this field, I hope that they can be used effectively, and not bent to the needs of the institution.

In addition to positioning this work in the academic field, a dialogue now ensues with the Familial Gastric Cancer Study at Cambridge University Hospitals, about how my work might be used to further understanding of how patients are experiencing living with the CDH1 genetic mutation. I will present my work in a lecture in Cambridge to the team of clinicians and researchers in 2018 (exact date to be confirmed). On completion of my website, the Cambridge Familial Gastric Cancer Study website will provide a link to my website. I will offer to give a follow-up lecture presentation to pre-clinical medical students on the 'Social Contexts of Health and Illness', taught by Dr Shirlene Badger, Senior Research Associate (Medical Sociologist), at Cambridge University.

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472 Mishler, *The Discourse of Medicine,* 1984.

473 NHS National Genetics and Genomics Education Centre, Telling stories, 2007-2014 <http://www.tellingstories.nhs.uk/index.php/background> [accessed 28 June 2107].

The focus of this autoethnographic work has necessarily been the narration of my experience. As a result, further work will be undertaken with others to share and expand ways of articulating experience of genetics. Following *The Joycean Society* and extending from my work *A Reading,* this will be achieved with a reading group, discussing the possible meanings of texts with other patients without taking meaning as the endpoint. I will trial this reading group with family members before contacting Sue Richardson, research nurse with the Familial Gastric Study at Cambridge University Hospitals, with a proposal for its inclusion as a workshop in the next HDGC Information Day. The multiplicity of meanings in *Finnegans Wake* partly affords this type of reading, and patients' medical notes, texts related to genetic illness or diagnosis, or a genetic script may serve this purpose well. By not adhering to narrative conventions, including closure, readers will explore the many possible meanings of living with risk without containing the essence of indeterminacy with which we are engaged.[474] In so doing, together we might offer alternatives to those narrative types associated with patient narratives that rely on and are driven by a search for and arrival at meaning. We might choose to resist the idea that the goal of patient narrative is often taken to be making meaning from illness, that illness has to be made meaningful to be endured.[475] Frequent conversations with my father remind me that not everyone shares my interest in art practice; indeed, our conversations often involve analogies with sport or agriculture (two subjects about which he is knowledgeable). Just as I have used my practice to articulate my experiences, others instrumentalise their practice and profession as a way of understanding their selves. Stephen Gould, for example, uses expertise from his professional life in articulating his illness. This will be considered in the reading group and readers will be invited to bring whatever they wish to their reading. On completion of this project, I will approach Jessica Kingsley Publishers to discuss publication.

Additional plans for circulating this work include producing a website, designed on the structure of my *Pé de Grue,* to act as concrete resource for doctors and researchers. I am

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[474] Jurecic, *Illness as Narrative,* p. 24.

[475] Of course, this is not surprising given the relation of meaning to narrative. However, my experience of genetic diagnosis and preventative surgery continues to be one of uncertainty.

pursuing an offer from Dan Wolstenholme to exhibit in Sheffield's Northern General Hospital Clocktower building.[476] I will exhibit *SEAMUS & ST298:402 – In Conversation, Adelante Series II, Silence for the Convalescing, ARS LONGA, VITA BREVIS, The Reading,* and invite people to participate in a reading group (see discussion on page 180). The location of the exhibition, in a teaching hospital, will attract audience members who will include patients and their relatives, practising doctors and nurses and those in training, and medical researchers. Publicising the exhibition will extend the invitation to other members of the public and an academic and art audience.

Narrative lies at multiple disciplinary intersections and it has only been possible to attend to some of these within the scope of this project. I see now that from the outset, despite being motivated by a desire to be open to all perspectives,[477] I was driven by an aim – to better articulate my experience, having not found a satisfactory way to do so previously – that was already leading me in some directions, while closing down others. I eschewed literature relating to therapeutic forms, such as psychoanalysis, due to my naïve understanding of their focus on therapy and healing and in light of my emphasis on telling or better articulating my experience. As my research progressed, the absences of these literatures in the field of genetics (and patient narratives thereof) shored up my decision. Further work should draw on those theories and perspectives not considered here, particularly those relating to therapeutic forms, to further open opportunities for insight and interdisciplinary exchange.

Word Count: 51, 072

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[476] Dan Wolstenholme is a Core Project Manager for the National Institute for Health Research, Visiting Research Fellow at Sheffield Hallam University, and Associate of Lab4Living – a collaboration between the Art and Design and Health and Social Care Research Centres at Sheffield Hallam University.

[477] Parker warns readers of the propensity in research to look to a readymade theory for explanation. Parker, *Qualitative Psychology*, p. 11.

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Appendix One: Digital Story Created with Patient Voices (DVD)

Appendix Two: Exhibitions and Presentations

Exhibitions

ST298:402 – 'CUT' (August 2014) Bank Street Arts Members' Exhibition, Sheffield

SEAMUS & ST298:402 – In Conversation – 'Design4Health' (July 2015), SIA Gallery, Sheffield

Adelante – Series II – 'Testing Testing' (August 2016), SIA Gallery, Sheffield

S:ST298.402 – 'Prescriptions' (supported by the Welcome Trust), The Drawing Room, The Beaney House of Art and Knowledge, The Beany Museum, Canterbury (April-August 2016)

Conference / Lecture Presentations

Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia – 6th Global Conference: Storytelling (May 2014), Lisbon

Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia – 'A patient Perspective', HDGC Information Day (June 2014), The University of Cambridge, Cambridge Biomedical Campus, Addenbrooke's Hospital, Cambridge

Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia – Live – In Dialogue: An International Conference for Artists and Researchers (October 2014), Nottingham Contemporary

Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia – Presented to pre-clinical medical students on the course 'Social Contexts of Health and Illness' at Cambridge University (November 2014)

A Conversation: Patient, Artist, Researcher – Method Conference (April 2015), Sheffield Hallam University

Book Fairs

Untitled 2014 – Leeds Artists' Books Fair (2014).

S:ST298.402 – exhibited as part of *The Editions*, a limited edition collection of artists' books and posters, stewarded and edited by Dr Sharon Kivland. Exhibited at Leeds International Contemporary Artists Book Fair (2015); the Hepworth Print Fair (2015), The Floating Library, Silverwood Park, Minneapolis, and Liverpool Artists' Book Fair (2015).

The Document – exhibited as part of *The Editions II: The Good Reader,* stewarded and edited by Sharon Kivland and published by MA BIBLIOTHÈQUE. Exhibited at Leeds International Contemporary Artists Book Fair (2015); The London Art Book Fair, The Whitechapel Gallery, London (2015)

Special Collections

S:ST298.402 – The University of Kent Special Collections and Archives.

S:ST298.402 – as part of *The Editions II* – Collection, Tate Gallery, Tate Library and Archive.

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'Emma Frances O'Connor, from Wikipedia the Free Encyclopaedia', in *Not Ever Absent: Storytelling in Arts, Culture, and Identity Formation,* edited by Sjoerd-Jeroen Moenandar and Nicole Kavner Miller, Oxford: Interdisciplinary Press, 2015.

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Reviews

Katie Sutherland, ‘Book Review: Stories of Becoming: Using Storytelling for Research, Counselling and Education’, Global Media Journal, Australian Edition, 11, 2017, 1–3.

Abstracts submitted

Abstract submitted collaboratively with Dr Sjoerd-Jeroen Moenandar to ‘Narrative and Wellbeing’, Narrare: Centre for Interdisciplinary Narrative Studies, The University of Tampere (October 2017)

Abstract submitted collaboratively with Dr Sjoerd-Jeroen Moenandar to the Fifth International Conference, European Narratology Network, ‘Narrative and Narratology: Metamorphosing the Structures’, Prague (September 2017)

Appendix Three: Muito Frágil: A Self-Contract

Self-Contract

I, Emma Frances O'Connor, agree and commit to take the following actions to ensure the prioritisation of my health while working. In so doing, I am fully accountable to my self.

- Do not leave the place where I have slept unless I have eaten.
- Ensure I have money for food and do not agree to any circumstances that will not facilitate this – no unpaid work until I can cover the costs of basic living.
- In the event of having to borrow money, do not feel so bad it makes me poorly. It is a short-term measure and I can pay back quickly and with interest.
- Accept offers of help.
- Ask for help when I need it. People will not know I need help unless I ask them.
- Do not get too angry with the receptionists at the doctors' surgery.
- Always take my medication.
- Do not feel bad reminding doctors about overdue tests or get stressed when chasing appointments.
- Under NO circumstances misuse pain medication. If I lapse, take measures so that this is not long lasting. Did I take painkillers to get more work done? Anticipate periods of intense work before deadlines and follow work plans to ensure there is no need for unhealthy working behaviours. If all else fails, postpone deadline rather than taking drugs to make me work for longer. Do not dwell on the fact that *The Argonauts* was only around a third written sober.
- Do not lie to pharmacists to *conseguir mas* medication.
- Do not spend days and nights going in pharmacies.
- Pain medication is not a substitute for food.
- Do not smoke; breathe air.
- Practice yoga.
- Smile as much as possible.
- Read novels at night to switch-off and relax.
- See friends at least once a week – it is not always enough to speak on the phone regularly.
- If I have lost weight, do not become overwhelmed by negative feelings associated with being thin. It is temporary. Do not waste time researching means to put weight on/increase curves/bust etc. Always have a stash of Complan. If weight drops, take

one per day in addition to meals. Eating regularly, not misusing opiate based pain medication, and not getting stressed should prevent this from happening.

- Do not compare my body to others. Do not sit in saunas in Portugal feeling like a shrivelled rat. Get the hell out of there.
- Speak to a friend and laugh at another friend's idea that a good solution might be to model myself on Kate Moss. Hilarious to think a supermodel is a good role model for bettering body image.
- Do not ever waste money or time on curve or bust enhancing creams.
- Do not buy high calorie baby food to put on weight abroad – their bad taste and texture makes them difficult to consume. They are troublesome to mix in hotel rooms. Take Complan on research trips.
- Anticipate situations when I may have to eat out alone. If I do not want to – for social or financial reasons – make sure there is somewhere I can eat well privately. Pot noodles sneaked in posh hotels are not sufficient.
- Be careful when walking all day that I eat plenty so that I do not start to lose weight.
- Do not stay in a hotel where I cannot afford a water in the bar.
- Make sure I inhabit an expansive and creative place – in my mind and physically. By taking all these actions, I will be happier and freer in my work. I am just deluding myself if and when I tell myself that my bad behaviours can help me work. (An addiction speaking?)
- When working away, try to stay in places where I will meet people. Expensive hotels, although good in lots of ways, are not good places to meet and/or interact with people.
- If I do end up in expensive hotels, the staff are often nice.
- When working away from home, make sure I have a contact in the area. Before I arrive, have a concrete plan to meet.
- Maybe find yoga/climbing classes to do while away, especially if away for extended periods.
- It is OK to talk to youngsters in the park and share stories about film cameras. Do not feel bad for not accepting all their offers to meet. Actually, maybe it is good to meet them.
- Do not travel unless fit to do so.

Completion date:
Reminder date:
Signature of contract maker:
Means of celebration on completion: