Malady and Mortality

Illness, Disease and Death in Literary and Visual Culture

Edited by **Helen Thomas**

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She dwells with Beauty—Beauty that must die;
And Joy, whose hand is ever at his lips
Bidding adieu; and aching Pleasure nigh,
Turning to poison while the bee-mouth sips.
Ay, in the very temple of Delight
Veil'd Melancholy has her sovran shrine,
Though seen of none save him whose strenuous tongue
Can burst Joy's grape against his palate fine;
His soul shall taste the sadness of her might,
And be among her cloudy trophies hung.

—John Keats, "Ode on Melancholy", 1819

Because I could not stop for Death –
He kindly stopped for me.

—Emily Dickinson, 1890

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INTRODUCTION

This book presents an original examination of visual and literary responses to, and representations of, malady and mortality. By focusing upon a range of creative and critical engagements with illness, paralysis, fatal disease, and attitudes towards death and bereavement, it examines powerful evocations of the human condition: through concepts of loss (of communication and control), critiques of cultural practice and revised subjectivities. Consequently, *Malady and Mortality* analyses the ways in which the ill and dying are presented as signifiers of difference, decay or solitude, or as virtual states of existence between life and death. However, as the narratives and artistic practices discussed reveal, the witness or experience of malady or approaching mortality also inspires moments of personal and social reflection, catharsis, social protest, medical celebration and critique, and provides insights into the processes of dying and death from ethical and legal perspectives. At times, this experience instigates utopian discourses predicated upon spiritual connectivity or virtual freedom, wherein the "self" is redefined beyond the parameters and constraints of the "body". Alternately, the experience of illness provokes notions of otherness and crises of "self-image" (Ashcroft 2002, 9) for the ill, their carers and loved ones; their former selves oscillating against new, vulnerable and precarious identities, sometimes exiled from the world of (healthy) others.

There are four major aspects to this examination. Firstly, this book contends that the experience of illness highlights the interface between life and death, the living and the dead, the body and the "virtual" self (Couser 1997, 35). As with Freud's concept of the "uncanny", which functions as a harbinger of death, the literary and visual texts discussed here articulate an experience of the "double", uncannily repeating the "life of the subject" as both a reflection and displacement, a mirror image that is both alive and decomposing as it moves towards death. As Nancy Mairs' experience of chronic incurable degenerative disease suggests: "Living with this mysterious mechanism feels like having your present self, and the past selves it embodies, haunted by a capricious and meanspirited ghost, unseen except for its footprints" (Mairs 1997, 298). Such narratives articulate the horrors of illness, the fears of a "living" death, the possibilities and problematics of "cures", and the reworking, restoration and "morphing" of the self or the body from one form into another

(Waldby 2000, 129). At times, the ill or dying person is seen as contaminated or grotesque as defined by Bakhtin in terms of its *ambivalency* and its ability to "outgrow itself" and "transgress its own limits"—"It is a pregnant death, a death that gives birth" (Bakhtin 1984, 25-6), "a demonic pregnancy" (Sontag 1978, 14). Yet within these visual and literary texts, the ill (and thus vulnerable) body is "preserved" within a "virtual" time and a virtual space at the very moment that organic decomposition sets in. As viewers and readers of such texts, we are both fascinated and horrified by what we see or read; we experience the uncertainty and crisis in a translated form (Waldby 2000, 129).[1] What distinguishes the chapters within *Malady and Mortality* is their extraordinary "witness" and "testimony" of the space between the dualisms of healthy/well, living/dying; the "gap" or "in-betweenness" which allows their artistic creators, narrators and readers to recognise "the devastation between posited thought and posited being, between power and exclusion from power" (Rose 1996, 10).

Literary and visual narratives of chronic illness not only present "dying" on display, but also manifest individual self-determination and agency. For the most part, contemporary culture treats death as the last remaining taboo, and thus endeavours to hide or repress its insistent manifestations. Like Freud's unconscious, Foucault's criminals and Kristeva's "utmost of abjection", the diseased body presents "the most sickening of wastes" (Kristeva 1982, 3-4). Autopathographies, however, re-establish the vital "presence" and necessary exposure of the ill body/dying "self" and review the problematic definitions of life and death amidst medicine's task to defy or restrict the power of death through prevention and intervention (Waldby 2000, 143).

Secondly, the chapters within this book suggest that autopathographies raise pertinent and urgent questions concerning definitions of life and the body that are of cultural, political and legal importance. As Moore and Brown observe, the "human body is not simply an object" (Moore 2005, 214). Whilst Cartesian concepts define the body as mechanical matter, a machine animated and organised according to mechanical laws yet inseparable from the mind, more recent definitions have interpreted the body as a system of dynamic interactions with its environment or as a process—always in "a state of becoming—and thus always in jeopardy" (Atkins 2005, 209).

For the medic and philosopher, Drew Leder, the living body's excessive, unpredictable, and complex "*non-functional* kinds of organic drive" complicate the "activity and agency of bodily materiality" propounded by medical models (Leder 1990). For scientists, life is an "elusive" force that animates living bodies yet exceeds its location in any particular body (Waldby 2000, 118). For cultural philosophers such as Foucault, life is a specific historical formulation rather than a transcendental quality—one with a "specifiable" archaeology—whereas recent cyber sciences and biopolitics have defined life as "code", as an information system "programmed" to transmit messages and data. Moreover, as Catherine Waldby argues, the qualities of vitality and mortality are "unstable"; dead animals can be cloned and revived, dead humans cryogenically preserved and tissue samples cultivated to produce immortal cell lines (as with the HeLa cell line). "Death has become increasingly uncertain", its borders "constantly breached and reconfigured" (ibid. 60).

Thirdly, this book examines concepts of subjectivity, the self, memory and mourning for the loss of the self. Foucault's work identified subjectivity in relation to power and subjection: "We understand who we are by public interpretation" (Atkins 2005, 209). Similarly, for Simone de Beauvoir, subjectivity constituted an "expression of the human body in a social matrix" (Atkins, 2). More recently, poststructuralism has highlighted what Terry Castle defines as the "modern polymorphous subject"—the multiple subjectivities that we inhabit and which are associated with ideas of the "ill" or "healthy" body, the "gendered" body, the "sexual" body, the "commodified" body, the body as a site of mystery and/or desire and, ultimately, the "dying" or "dead" body. Such subjectivities or concepts of self and body divide and interact with each other in a complex and usually productive process of self-definition, re-definition and reproduction. However, with illness in particular, that process threatens to become out of control and often tends towards loss of communication, loss of agency and loss of self.

Whilst mourning suggests the lamenting of "loss" and melancholia, a refusal to "let go", the chapters contained here examine the complex personal, cultural and literary intersections of death and the poetics of grief. As Gillian Rose has suggested, mourning has "*political* consequences" as it acknowledges the "creative involvement of action in the configurations of power and law" (Rose 1996, 12, 103): Grief, then, displays the "thrall in which our relations with others hold us, in ways we cannot always recount or explain…in ways that challenge the very notion of ourselves as autonomous and in control"—"We're undone by each other. And if we're not, we're missing something" (Butler 2004, 23).

Fourthly, this book interrogates medical and legal responses to illness, disease and treatment, most especially laws relating to property, privacy and genetic coding. Representations and evocations of illness, dying and death are seen to break down boundaries of intimacy between the private and public self, yet also raise the emotional and legal complexities of posthumous publication, invasions of privacy and property as proscribed by legislation, as well as violations of the natural "laws" of genetic coding.

Autobiography/Pathography

Before 1950, most personal accounts of illness took the form of private letters to friends and family, or as literary fictions that represented malady or mortality symbolically, as a symptom of society's disorders and sociopolitical "ailments". From the 1950s onwards, book-length pathographies appeared, an emergence which Couser links to the civil rights and liberation movements of the post-war period (Hawkins 1993, 3). Within such texts, which Couser names "autopathographies", the complex relation between bodily dysfunction and personal narrative is negotiated amidst perceived threats to the ill person's identity, an increasing awareness of one's mortality, a disruption of the "apparent plot of one's life" and at times, a disparity between the author's inner and outer sense of self (Couser 1997, 5, 67). Yet autobiographical introspection or visualisation of illness or "bodily dysfunction" also tends to heighten the individual's sense of consciousness, contingency and agency. However, such opportunities are not always available to sick or disabled narrators and thus inspire the creation of representation and witness by close friends and carers who take on the role of artistry and production (ibid. 6). In this respect, this book differs from those exclusively focused upon personal or fictional representations of illness and dying, and instead combines personal accounts with those by medics, practitioners, carers, the media and the bereaved, whilst highlighting their critical and creative interface.

As patients endeavour to take control of their own subjectivity in the face of medical objectification, narratives of illness, as Arthur Frank notes, manifest themselves in three main formats: "restitution" narratives (advocating a restoration of health), "chaos stories" (in which the voice of the sufferer becomes lost amongst the loss and chaos) and "quest stories" which "afford the ill person a voice as a teller of her own story"; together with a sense that something is to be gained from the experience, even though the object of the quest may never be fully defined (Frank 1991, 115; Cousner 12). This critical collection examines a transhistorical selection of each of these forms in the light of concepts of medicine, authority, agency, property, power and loss.

Digital Economies

Recent digital technologies have not only enabled the interface between virtual and actual space, but radically changed the ways in which the "corrupt" or diseased body can be represented, analysed and communicated. New forms of medical imaging such as computed tomography scans (CT) and the Visible Human Project (VHP) read the body's interior as "digitised information configured on a computer screen" whilst the "transfiguration of the human body into digital substance" renders the previously private, sacred space of the body as globally visible and available (Waldby 2011, 5-6).

From the perspective of the "ill" person, digital information networks, forums and internet databases have enabled communication and interaction between "patients" and "unseen others" on a global scale. This has allowed for unprecedented forms of interaction and collaborative partnerships—or what Jenkins calls a "changed sense of community, a greater sense of participation, less dependence on official expertise and a greater trust in collaborative problem solving" (Jenkins 2009, 9)—that reaches far beyond the realm of traditional "medical" relationships and the relatively limited availability of artistic and literary production. In digitized, virtual space, "reality" can be perceived as being "free" from the body. Moreover, virtual spaces offer the existence of bodily "simulacra" and the possibility of merging different worlds, real, physical and conceptual, that liberates the body—ill or otherwise—from physical and even genetic existence. Digital economies allow e-existence that surpasses the constraints of the body, offering "gateways to a new era" not unlike the postnatural digital domain of the cybernatural (Cubbitt 1996, 238).

Within pre-digital culture, medical knowledge and advice was primarily communicated via private, public and medical exchanges—relatively slow and circumscribed forms of dissemination and collaboration. More recent digital technologies have changed not only the speed and availability of such communications, but also the parameters and gatekeepers of medical knowledge, by creating online "patient" communities and systems of knowledge and exchange. These digital economies and modes of communication have revised traditional and professional boundaries between the medical world and the patient, between the public and private "self", thereby enabling transformative, collaborative partnerships and the creation of new digital communities on a global scale. Within these communities, patients have increasingly visualised their location in a "matrix of networks", including family, friends, trial participants and medical associations and societies. They have also demanded partial or absolute control over the practices linked to their own health and sought multiple forms of expert and non-expert advice (Novas and Rose 2005, 239). “Virtual” internet communication within the digital dimension has not only prompted revisionary concepts of the “healthy” and “ill” body but also initiated new responses to the loss of “physicality”, transcendence of the “real” and the multiplicity of the “self” and “identity” within different contexts.

As Gunther Eysenbach comments, this reflects a “state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve healthcare locally, regionally, and worldwide by using information and communication technology” (2001). “E-health” has the potential to enable professional collaboration and sharing of information; electronic communication between patient and healthcare professionals; access to electronic resources by professionals and patients; as well as medical research using powerful computing and data management capabilities to handle large amounts of heterogeneous data. Unlike diary entries, digital texts, such as emails, are easily reproducible and easily shared with others (possibly against the author’s wishes); and unlike first-person narratives, they offer the possibility of two-way dialogues, which complicate ideas of property and posthumous ownership. We read the narrator’s responses to his/her physical and/or mental decline as they occur, beyond the comforts of subsequent editorial revisions or superimposed plots. With digital entries, “reader and writer proceed together into the unknown” (Couser 1997, 54). Furthermore, digital technologies offer distinctly “modern” forms of death, dying and mourning, which in turn have altered our concepts of the body, of life, and of grieving (Gilbert, 245). “Virtual cemeteries” for example, offer virtual memorial gardens and cyberspace memorials to the dead, in which “visitors” with a common bond can “share their losses” and “continue to celebrate” the lives of loved ones.[2] Such constructions, argues Gilbert, have arisen as a consequence of the contemporary medicalisation of death—its elimination from public ceremony and its restriction to private acts of dying and mourning—as well as the “rejection and elimination of mourning” (ibid., 247). However, at the heart of all endeavours to reveal the experience of malady and mortality, a silence persists, a void of inexpressibility and inaccessibility that haunts visual, literary and digital texts as they endeavour to “reveal” and produce meaning.

Malady and Mortality is divided into three sections: Part I examines “Illness and Dying: Medical and Patient Practice”, Part II examines “Illness, Memory and Representation” and Part III explores “Art and

Mourning”. In Chapter One, “‘First, Do No Harm’: The Interplay Between Medical Culture, Medical Education and the Medical Humanities in Treating Medicine’s Self-Induced Maladies”, Alan Bleakley interrogates the “structural maladies” in medical education and training and advocates the important role of the medical humanities in the transformation of medical practice, as well as historical and cultural assumptions about the body, health, illness and disease. In Chapter Two, “‘My Week with Jeff’: Fostering Emotional Wellbeing and Empathy in Medical Students through Creative Writing”, Anne Taylor and Aled Picton examine the emotional challenges facing medical students and present a compelling account of the impact of the humanities upon the personal and professional development of student doctors. Chapter Three, by Julia Kennedy, “In the Blood: Mapping Narrative Circulation in Online Leukaemia Networks” presents a personal account of the role of online communication and medical-digital citizenship in the context of a diagnosis of chronic lymphocytic leukaemia. In “Families and Photography: An Everyday Lens on End of Life” (Chapter Four), Lorna Warren and Julie Ellis explore photographic practices amidst couples and families facing end-of-life circumstances and infant death, whilst Annastasia Maksymluk, in Chapter Five, “Patient Identity: A Visual and Critical Response”, presents a personal account of her recent experience of “being a patient”, her photographic practices whilst hospitalized, and the function of art in the context of patienthood and medical identity.

In Part II, “Illness, Memory and Representation”, Fiona Johnstone examines the erotogenic and intimate work of Mark Morrisroe towards the end of his life in “The Pin-Up and the Corpse: Erotic Self-Representation and Terminal Illness in Mark’s Morrisroe’s AIDS Self-Portraits” (Chapter Six). Chapter Seven, “Treble Exposure: Fissured Memory in Eva Figes’ Fiction” by Marilena Parlati examines Figes’ memoirs and faction in the context of ageing, trauma and memory, whilst also highlighting the processes of fractured narrative, editorial control and revision. In “The Unborn Undead—A Journey With a Bi-Fold Body” (Chapter Eight), Joanne “Bob” Whalley presents a personal account of “zombie experience” in order to explore the cultural and philosophical parameters of “expectant management” and miscarriage and articulate narratives of grief positioned within a feminine terrain. In “Mary Robinson, the Press and Representations of the Body” (Chapter Nine), Chrisy Dennis provides a compelling account of the interconnections between the celebrity’s declining health, her (politically promiscuous) lifestyle, and the treatment of her “body” by the press and in light of eighteenth-century political upheavals. Kym Martindale’s analysis of Frances Bellerby’s writing, "'Out of Place in Eternity': Doing Time in the Poetry of Frances Bellerby" (Chapter Ten) highlights the locus of loss, violence and destruction that haunts Bellerby's poetical works. In "Freeze Frame: Well-Being, Paralysis And Dying in Three Contemporary Texts" (Chapter Eleven), I explore autobiographical representations of paralysis in relation to physical entropy and revised subjectivities, whilst Michele Aaron's chapter, "Watching Others Die: *Dying at Grace* (2003), Spectatorship, and the Ethics of Being Moved" (Chapter Twelve), explores film's potential to "represent dying differently" and promote co-experience and *shared* social exchange amidst the processes of death.

Part III of *Malady and Mortality* focuses upon the function of art in the context of mourning and presents a new focus upon those who are bereaved and those who have acted as carers for the deceased. In her visual essay, "Clothes For Death / Odjeća Za Smrt" (Chapter Thirteen), Margareta Kern's photographs capture the funeral and mourning traditions of women in Croatia and Bosnia-Herzegovina as they prepare for their own deaths—choosing the clothes they wish to be buried in. In their chapter "Design of Death" (Chapter Fourteen), graphic designers Nikki Salkeld and Ashley Rudolph interrogate traditional symbols of death and analyse the ways in which creative practice can both revise and develop new symbolism as means of generating communication, meaning and processes of transition. Chapter Fifteen, "Grief, Illness and Death in Contemporary Photography" by Montse Morcate and Rebeca Pardo explores the use of art photography by the bereaved in order to pay homage to the deceased loved one and facilitate the grieving process, but also to capture and grieve the "subject" in the midst of dementia and schizophrenia. In "Imag(in)ing the Dead as Angels" (Chapter Sixteen), Tony Walter explores the function of contemporary images of the angelic dead within digital, literary and visual contexts as a means of continuing bonds between the living and the dead. Chapter Seventeen, "Death in Environmental Art: Self-Eradication to Mass Mortality" by Alex Murdin, situates death amidst both environmental concerns and artistic responses and examines the role of art amidst ecological crises and environmental disasters. Finally, in Chapter Eighteen, Lucy Willow's "The Last Photograph: A Microscopic View of Transience, Mourning and Loss" presents a poignant narrative of the author's artistic practices in the context of grief and personal loss, thus highlighting the integration of the memory of the dead within the present and shared empathy and intimacy that can be prompted and revealed by an image.

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Websites

http://www.virtualmemorialgarden.net
http://gpcemetary.homestead.com/files/Welcome.html.

Notes

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[1] I am using Elisabeth Bronfen’s concept of “still life” and Walby’s ideas concerning the VHP and A-Life here.

[2] http://www.virtualmemorialgarden.net;
http://gpcemetary.homestead.com/files/Welcome.html.

PART I

ILLNESS AND DYING:
MEDICAL AND PATIENT PRACTICE

CHAPTER ONE

"FIRST, DO NO HARM": THE INTERPLAY BETWEEN MEDICAL CULTURE, MEDICAL EDUCATION AND THE MEDICAL HUMANITIES IN TREATING MEDICINE'S SELF-INDUCED MALADIES

ALAN BLEAKLEY

Introduction

The injunction to "First, do no harm" (or "Above all, do no harm") is often wrongly ascribed to Hippocrates from the late fifth century BC—but a similar maxim does appear in the later Hippocratic corpus in the third century BC as "abstain from doing harm". It is likely that the seventeenth-century physician Thomas Sydenham first coined the exact phrase (Smith 2005). Whatever its origin, "First, do no harm" is lodged in the medical culture's psyche and the public imagination as the main guiding principle for doctors. However, medicine does do harm. The paradoxical effect of medical interventions themselves causing harm to patients—iatrogenesis (literally, having its origins in the healer or doctor)—has been documented closely in modern times since Ivan Illich's *Limits to Medicine* (1977), the opening line of which infamously stated that: "The medical establishment has become a major threat to health." Iatrogenesis includes the side effects of drugs, hospital acquired infections and medical or surgical error.

There is, however, another face to iatrogenesis, a face that turns away from patients and inwards to medical culture itself: medical students and doctors suffer symptoms through the structural effects of studying medicine, either from historically ingrained habits of socialization such as stressful working and learning conditions, or from structural factors such as working in hierarchies that refuse democratic participation (Bleakley, Bligh and Browne 2011; Bleakley 2014). Habitual patterns of medical education and training from undergraduate to postgraduate (specialty) levels (re)produce unnecessary malady, where good doctors are typically formed not because of, but in spite of, medical education.

While public focus, through the media's attention, is currently on the perilous state of a seriously under-resourced UK National Health Service (NHS) said to be close to collapse, little attention is paid to how the quality of the medical side of that service is provided through medical education or how the institution of medicine itself—historically a conservative and authority-led structure—must adapt to contemporary political forms of health provision as democratic, team-based and patient-centred (Bleakley 2014). Structural hierarchies within medicine combined with forms of work-based medical education that generate iatrogenic distress are themselves in need of treatment. While patients' illnesses, diseases and deaths are the foci for medicine, will medicine also face up to its own death wish and treat its structural maladies in an effort of self-care, or "first, do no harm to oneself"?

Shaping the Fabric of the Sensible Through Medical Education

In Mark Haddon's novel, *The Red House*, a rare condition that causes a mother's baby to be stillborn is diagnosed by a junior doctor (Haddon 2012, 103). Disconcertingly, the doctor not only "seemed pleased with himself for knowing the biology behind such a rare syndrome", but also "gave the impression that she (the mother) was meant to feel pleased too, for having won some sort of perverse jackpot". Haddon's observation can be seen to confirm the intuitive rationale for the inclusion of the medical humanities in medical education—to "humanize" those doctors who place "cases" and smart diagnoses before persons and feelings.

But this need for humanizing runs far deeper than individual doctor's practices, to the culture of medical education and the institution of medicine itself. Two intertwining cultures shape doctors' practices and identities—the clinical culture of medicine and the pedagogical culture of medical education. Medical education need not act as handmaiden to normative medicine, but can formulate resistance to, and critique of, the institutional norms of medicine where these are perceived as unproductive to patient care, collaborative inter-professional teamwork and doctors' self-care. The structure of medicine itself, its habitual practices, must be challenged and adapted if we are to produce doctors who are technically good but also deeply connected with the interpersonal aspect of their work. Further, medical education incorporating the medical humanities is the vehicle for such change. At the core of this sea change is the democratizing of medicine—shifting medical practice from an authority-led hierarchy that is doctor-centred to a patient-centred and inter-professional clinical team process. This is a political challenge.

Running parallel to this political issue is an aesthetic challenge—shifting an instrumental and technical mindset that permeates medicine, shaping it merely as technical craft, to a medicine of qualities, traditionally called the "art" of medicine. Just what constitutes that art is what makes up the inter-disciplinary field of the medical humanities in medical education: communicating sensitively with patients and colleagues; close listening in receiving the patient's history; close noticing in the physical examination; making sense of the stories that patients tell and adapting interventions accordingly; managing an identity as an expert or a connoisseur in a specialty; critically and reflexively understanding the fabric of medical culture itself; and critically and reflexively understanding historical and cultural assumptions about the body, health, disease and illness.

Medical educationalists have introduced many curriculum innovations to address the need to educate for new forms of healthcare emerging for the coming century. These include professionalism, communication skills, inter-professional teamwork, patient-centred practice, early clinical experience, structured work-based learning and learning through simulation. However, some of these innovations have been counterproductive. Rather than educating and widening the sensibilities of students, such innovations can produce insensibility and narrowing of focus. As a result, we need to fundamentally reformulate medical education, but this in turn needs a re-structuring of the institution of medicine. As noted above, a politicized and aestheticized medical education can act as the grit that produces the pearl of an enlightened medical culture or institution of medicine—one that is fundamentally and authentically democratic rather than autocratic or meritocratic posing as autocratic.

In the context of critical theory applied to social institutions, the French philosopher Jacques Rancière (2013, ix) describes how "ways of perceiving and being affected" are constructed institutionally, particularly through education and popular culture. In other words, how each of us senses and how sensibilities are shaped is an issue of institutional framing. Such frames are subject to historical and local traditions ("this is the way we do things around here"). Ways of taking in the world around us and making judgements about it, such as what is noticed, appreciated and what goes unnoticed are, suggests Rancière, subject to "modes of perception" (that I shall call "sensibility") and "regimes of emotion" (that I shall call "sensitivity"). These are "policed" by institutions and their representatives who hold power and authority to shape a fabric of the sensible. At the same time, it is possible that those who are subject to learning how to perceive and feel challenge the normative ways of being educated into these states. Rancière (2010) calls this “dissensus”. Dissensus—the opposite of consensus—is a neologism from the 1960s. It is equivalent to the more commonly used “dissension” that is derived from the Latin *dissensio* and *dissentire* meaning a “difference of opinion”. Democracy relies as much on dissension or dissensus as it does on consent or agreement.

If we transfer Rancière’s model to medicine and medical education, we can describe an aesthetic regime of medicine with its own expert modes of perception that are controlled and distributed by those in authority—senior clinical teachers. My argument is twofold—first that the capital of the sensible (the fabric of the sensible within medicine, or how things are perceived and felt) is not distributed fairly by senior medical teachers or clinicians in general (as representatives of normative medical culture), where it is not shared democratically with students, patients and other healthcare professionals such as nurses. Second, some current practices in medical education—both unconsciously as unintended consequences and consciously as intended consequences—produce insensibility in medical students. The political and aesthetic structures of medical education need to be radically reformulated and I suggest that this can be achieved through incorporating the medical humanities into medical education as core and integrated provision. By the “medical humanities”, again I mean several things: applying the arts and humanities to improve medical education and practice (functionally, through for example education of the senses to improve clinical acumen in diagnoses; and politically, through challenging the values that form medical practice); emphasizing the intrinsic beauty of biomedical science and the artistry of medical practice; and developing the humanity of medicine.

A redistribution and reconfiguration of the sensible—or the capital of sensibility—would render medical students and doctors more sensible (acute) rather than more insensible (blunted) as better at close noticing, valuing, judging and offering insightful support to patients and colleagues alike. For the sake of clarity, I will again make a distinction between (1) ways of perceiving as “sensibility”, the heart of which in medical work is close noticing and diagnostic acumen; and (2) ways of being affected, or openness to the conditions of others—particularly the experiences of patients and colleagues—as “sensitivity”. Current ways of educating perception through medical education may be misguided or historically crystallized in the ways that they restrictively structure what is worth noticing and valuing. Through the medical humanities, we can aim for a re-education of sensibility and sensitivity, where medical education again can, paradoxically, render medical students and doctors insensible or anaesthetized. This re-education can widen to a politicizing of students, patients and healthcare practitioners to promote the democratizing of medicine. Bringing medicine face to face again with its own maxim "first, do no harm"—to patients in regimes of practice and to medical students and junior doctors in regimes of training—is an intertwined political and aesthetic issue: to turn the production of insensibility into the production and fair distribution of sensibility.

The Role of the Medical Humanities in Addressing Symptoms of a Malfunctioning Medical Education

The aim of the medical humanities in medical education is, I suggest, a redistribution of the sensible to create a common wealth. In Rancière's (2013) phrase, the project of the medical humanities is then enormous, no less than a series of "transformations of the sensible fabric" of medical practice. Such a reconfiguration promises to restructure performance through a reformulation of sense experience and diagnostic acumen, narrative acumen and ethical (professional) behaviour.

The single most important force shaping the structure of medical practice is work-based medical education—the clinical years of undergraduate study and the first years of junior doctoring. It is here that influential clinical teachers and teams largely shape the sensibilities of future doctors in a cognitive apprenticeship. It is experts—mainly consultants or specialists—who hold sensibility capital (diagnostic and treatment acumen: how to do a physical examination and take a history, how to diagnose and how to treat both generally and within specialties). Experts can distribute this capital as they wish to those who do not hold it—not just medical students, but also patients and other healthcare practitioners. Most clinical teachers will be generous in their intentions in sharing such capital in an equitable way. However, if they are not also expert educators as well as expert clinicians, such sharing of capital can backfire or be misplaced. As an unintended consequence of medical education, again what can result is an increase in insensibility amongst students—a kind of numbing or insensitivity. How does this show in symptoms?

A slide from idealism into cynicism has for too long characterized the later years of medical school as an unintended consequence of medical education. In the post WWII years, this slippage was pronounced, as Howard Becker (Becker et al. 1961) described in stark detail for the "boys in white". Twenty years later, Robert Broadhead's (1983) description of undergraduate medical education shows the same slippage, now technically referred to as “empathy decline” and “moral erosion” linked to communication “hypocompetence” or underperformance (Platt 1979). While white coats have disappeared from medicine in many countries, the permanent stains of empathy decline and moral erosion amongst medical students have remained—still vigorously discussed in online communities today (Remen 2012).

Paula Nunes and colleagues (Nunes et al.. 2011, 12) show that empathy decline is a phenomenon appearing across healthcare students in general, with medical, dental and nursing students showing significant decline even in the first year of study “with a change from idealism to realism”. Erosion of empathy has been described as a wider cultural phenomenon linked with rising inequalities. Empathy decline is linked to the onset of “moral erosion” (accepting unethical behaviour as a norm) and poor self-care. These conditions form a fault-line in medicine linked to unacceptable rates of medical error.

The distinguished physician and best-selling novelist Abraham Verghese, now working at Stanford University Medical School in California, suggests that medical students’ and junior doctors’ potential empathy decline and moral erosion are best nipped in the bud through extensive and intensive bedside encounters with patients supported by highly considerate and insightful teaching faculty (Cohen 2009). It is patients—and not medical schools—who teach empathy. It is literally in staying in touch with patients that medical students in particular can establish a powerful sensibility and sensitivity without having this drained away, blocked, or confused by established practices of bedside teaching—such as “pimping” —that model moral erosion. The (mal)practice of “pimping” is described by James Marcum (2013) as a senior doctor asking unnecessarily interrogative, demanding and gruelling questions of junior doctors and medical students leading to humiliation and degradation.

Marcum draws on the Grand Round scene from Margaret Edson’s (1999, 46) play *W;T* (or *Wit*) to describe how the bedside examination can be, in Edson’s words, “Full of subservience, hierarchy, gratuitous displays, (and) sublimated rivalries”, in other words the very conditions that generate insensibility in medical students as medicine stutters again in its long walk to freedom or authentic democracy.

> The scene begins with the chief of medical oncology, Harvey Kelekian, and five clinical fellows, including senior fellow, Jason Posner, entering Vivian Bearing’s room. Bearing is a professor of English and has stage-four metastatic ovarian tumor. She is undergoing chemotherapy and is currently receiving the second cycle. Kelekian acknowledges Bearing’s

> presence, and Posner inquires perfunctorily how she is "feeling" today to which she responds "fine." Posner then exposes Bearing's abdomen and recites the facts of her case, often palpating anatomical areas of involvement. After recitation of the clinical facts, Kelekian asks the fellows what side effects are associated with the drugs used to treat Bearing's cancer. One fellow begins to answer only to be cut short by Posner, who dismissively retorts that the side effect "goes without saying." The playwright notes that the other fellows resent Posner, as he belittles their attempts to list the chemotherapeutic drugs' side effects. At last, Kelekian asks if any other side effects are evident, to which the fellows are unable to answer. Kelekian asks them to use their eyes and after the fellows fail to provide the correct answer, he points out the patient's hair loss. The fellows protest that this side effect is obvious, and Kelekian calls on Posner to expound, who then begrudgingly complies. The scene concludes with Kelekian urging Bearing to receive the "full dose" of the chemotherapeutic drugs and to "keep pushing the fluids." Finally, he admonishes Posner to perform his clinical duty and thank Bearing for her cooperation, which Posner does mechanically. Bearing is left with her abdomen exposed and comments on how "grand" the experience was.

Verghese points out that the hands-on physical examination is not limited to on-the-spot diagnostics, but affords the ritual of patient contact in which both trust is set up and a doctor's identity is confirmed. It is a context in which difference is acknowledged and celebrated. In a *New York Times* interview (Chen 2009) Verghese says:

> The importance of the ritual of one patient baring his or her soul and body cannot be underestimated. Rituals are terribly important to human beings because they signify transformation. This is how you earn your right to say, "I am your doctor." If as a doctor you shortchange the ritual, you end up making patients feel you aren't interested. They lose trust.

The bedside examination, then, is part of a doctor's performance and learning such a performance, as a medical student, is central to the shift in identity construction from student to trainee doctor. We must then, as medical educators, be careful not to educate for mis-identification (through the production of insensibility) in not exploiting the full potential of bedside teaching. Patients come to trust doctors with a good bedside or consultation manner and we know that the therapeutic relationship between doctor and patient affects the healing process (Roter and Hall 2006). So, in short, the warm bedside and consultation manner that accompanies a technically proficient physical examination diagnosis marks out a key aspect of a doctor's or trainee doctor's performance, but is in danger of being supplanted by cold and distancing imaging technologies and testing.

Over a century ago, in the early 1900s, a similar scenario was being discussed amongst a community of medical educators in London. Sir Robert Hutchison noted the need to openly support the warm art of medicine in the face of an increasingly dominant cold science (Shankar 2010). Hutchison's petition concluded:

> From putting knowledge before wisdom, science before art, and
> Cleverness before common sense;
> From treating patients as cases;
> And from making the cure of the disease more grievous than the
> Endurance of the same, Good Lord, deliver us.

In Hutchison's era, the "art" of medicine meant bedside manner and diagnostic acumen. Both were assumed to flow from character virtues, such as altruism, that in turn were an assumed product of a liberal education. Warner (2011, 92) notes that late nineteenth- and early twentieth-century "celebrity" doctors, such as William Osler, called for "a rehumanisation of medicine" and a cultivation of "an ideal of the 'gentleman-physician' well versed in the classic liberal arts". This ideal of the doctor with the "right stuff" has lingered. As late as 1975, the UK Royal College of Physicians felt it important to say that their membership examination requirement "remains partly a test of culture, although knowledge of Latin, Greek, French and German is no longer required" (McManus 1995, 1144).

Science study has, however, progressively claimed and partially eroded the ground of a liberal education once thought to be an essential background for practising medicine. The benefits of scientific and technological advances in medicine are clear and we might say that the erosion of the art of medicine is a small price to pay for advances in population health. However, this erosion of the human face of medicine is a symptom of a wider structural problem—that of the continuing dominance of hierarchical clinical teamwork that favours doctors and marginalizes other healthcare professionals and patients. There is an ongoing iatrogenic (medically-caused) "epidemic" (Starfield 2000) of medical error, where an estimated 70% of such error is grounded not in technical mistakes, but in poor communication between doctors and colleagues within and between clinical teams (Xyrichis and Ream 2008). Medical error has been noted as the fourth biggest killer after cancer, cardiac disease and respiratory disease, with an estimated 200,000 deaths per year in the USA (Harmon 2009) and 40,000 per year in the UK (Barron 2009; Office for National Statistics 2010).

Medical education has, logically but mistakenly, responded to this communication "hypocompetence" (Platt 1979) problem through intensifying instrumental training in communication skills such as empathy and breaking bad news (Bleakley 2014). However, thirty years' worth of developing communication skills in undergraduate medicine—largely through simulation, as a quasi-scientific laboratory-based training—has not addressed the continuing high level of medical error. Learning communication as an instrumental skill may be necessary, but does not offer a sufficient condition to address poor practices in clinical teamwork and patient consultations. Something else is needed. The deeper problem may be the unrealized democratization of medical culture, a shift that would challenge the root symptoms of poor communication in clinical teams—hierarchy and unproductive authoritarianism (Bleakley 2014).

Patently, educating for a virtuous character through a liberal education has never humanized medical practice—and "humanizing" is a cloudy term in danger of slipping into piety. Now we also realize that learning communication skills instrumentally is failing to humanize medicine. It may be, however, that the medical humanities can provide the extra curriculum dimension to educate for both patient-centredness and democratic team practice. Medicine requires a medium for translation of clinical scientific knowledge into patient care and that medium may be the medical humanities.

The Distribution of the Sensible

The writer Mark Slouka (2010, 168) suggests that "democratic institutions do not spring up, like flowers at the feet of the magi, in the tire tracks of commerce. They just don't. They're a different species. They require a different kind of tending." But what is it that nourishes the development of an authentically democratic institution? Slouka suggests that "(T)he humanities…are a superb delivery mechanism for what we might call democratic values". To "the humanities" we must explicitly add "the arts". Together, will the humanities and arts in medical education provide the contextual media through which democratic practices can be established in medicine, leading to improved patient care?

I will draw on one main theoretical framework to inform the discussion of why the medical humanities are needed for medical education. I adapt a post-Marxist model developed by Jacques Rancière (2006, 2010, 2013), introduced above, exploring the distribution of the fabric of the sensible (or sensibility) in culture to argue that current habitual practices in medical education may paradoxically restrict, rather than enhance, quality of learning. The argument again links a political call to democratize medical practice with an aesthetic call to promote education of the sensible, or sensibility. If medical education produces insensibility, either consciously to maintain existing power structures, or unconsciously as, say, a form of defence against ambiguity, how might this be countered? The overall argument of this chapter is that the medical humanities offer a primary form of resistance to production of insensibility, where such insensibility is a malady of medical education reflecting medical culture's blunt aesthetic and pyramidal politics. Or, there are various ways of employing the medical humanities to re-distribute sensibility capital held by expert clinical teachers fairly amongst students, patients and marginalized healthcare practitioners. The medical humanities even out or re-distribute lumps in the fabric of the sensible produced by unfair concentration of capital; or—the medical humanities repair and restore rents in the fabric of the sensible produced by interested parties, sometimes violently and unfairly, appropriating sensibility capital.

It is not of course that medical education in general intentionally goes out of its way to create conditions that stifle creativity, imagination, sensitivity and sensibility in the work of medical students. Rather, the production of insensibility is a largely unintended consequence, or paradoxical effect, of dominant and unexamined practices in medical education that amount to a medical "mis-education". I borrow this awkward, but compelling, term from Paul Goodman's (1964) classic *Compulsory Mis-education*, first published in 1964 as a scathing attack on the American schools system.

In medical education, dominant discourses and habits of practice lead to symptoms that include:

1. Iatrogenic stress—the production of excessive amounts of stress, leading to anxiety, depression, suicide ideation, depersonalization, drug and alcohol abuse and burnout due to the institutionally habitual, gruelling forms of apprenticeship and socialization into medicine.

2. The production and distribution of insensibility, or institutional "dulling" through medical education. A contemporary characteristic of this is the trend towards abandoning teaching of hands-on physical examination for medical students with the rationale that machine-based, remote testing has now largely replaced hands-on diagnoses as the most reliable method. As a consequence, as noted above, the arts of auscultation, palpation and percussion are fast disappearing (Verghese 2011). This, partially conscious and partially unintended, consequence of

medical education is exacerbated by typically having to learn and work in dulling clinical environments that are tolerated rather than critically refused as part of the symptom pattern of medical education's machismo.

3. Mistaking complex and nonlinear medical work for the complicated and linear. This centres on attempting to translate the generalizations of population-based and evidence-based medicine into treatment of the individual patient. Where a jigsaw mentality pervades evidence-based generalizations (work out the parts and they will add up to the whole), the individual's complex needs may be misjudged (the whole is greater than the sum of the individual parts).

4. Medicine's literalism—a combination of reduction of the nonlinear complex to the linear complicated, the abstract to the instrumental and problem stating to habitual problem solving. These factors add up to an intolerance of ambiguity and uncertainty, the central feature of both an authoritarian institutional structure and personality type. Literalism—the need to translate the conceptual into the concrete and the abstract into the instrumental—shows in the typical reductive "case presentation", where the "chief complaint" diagnosed by the doctor replaces the more complex "chief concern" of the patient (Schleifer and Vannatta 2013); and where the certainties of indicative thinking and language ("this is"/ "certainly") replace the admittance of ambiguity characteristic of subjunctivizing ("this may be"/ "possibly/ maybe") (Bruner 1986; Good 2000).

5. Arrested development of medicine, in psychoanalytic terms, as an "anal" culture and institution with associated character types, typified by authoritarian structures such as hierarchies and the need to control and be controlled. This has a subset of symptoms that can be characterized as paternalism, or what Alfred Adler (1927/2009) called the "masculine protest". An outcome of these symptoms is the inability for medical culture to progress towards authentic democratic forms of work (Bleakley 2014).

6. Iatrogenesis, where medical interventions cause unintended harm. This is relatively rare for technical interventions, but far more common in terms of mistakes arising from the non-technical side of medical and surgical work, such as poor communication with colleagues in clinical team settings or between doctor and patient.

7. Empathy decline and moral erosion in medical students.

8. Poor self-care among medical students—linked to medicine's habitual institutional pride in supposed heroic invulnerability.

In order to resist this slippage into production of the insensible, where medical education adds to a general anaesthetizing and depoliticizing of students rather than an aestheticizing and politicizing, I will argue that the medical humanities in medical education can promote:

1.Redistribution of the sensible to allow for new ways of noticing and appreciating. This is fundamentally a re-education of the senses.

2. Development of practice from an "anal" arrested stage to a "genital", collaborative and progressive stage in which tenderness and collaboration are seen as strengths rather than weaknesses, in a challenge to the dominant and controlling patriarchy gripped by an outmoded ideology of heroic individualism.

The Distribution of the Sensible is an Historical Phenomenon

What we do, say, think, imagine and even feel is regulated historically, culturally and socially (Elias 2000). For example, spitting in public was once acceptable but is now frowned upon; how and when we cough, sniff, blow our noses, or eat our food are subject to layers of cultural habit. We blush even when we are not in company; we dissimulate in order to not lose face or offend another. "Manners" in a culture develop historically and become normalized and habitual—Norbert Elias (2000) refers to this as "the civilizing process". Ivan Illich (1985) describes the history of the water closet, to show how the private toilet was developed not out of concern for hygiene but for the growing practice of privacy (hence the "privy"). Privacy in turn is part of a major discourse centred on the forming of the "individual", giving rise not only to the cults of autonomy and celebrity, but also psychiatry and psychology as the institutional regulation of personality (Foucault 2006).

Practices and behaviours arising from the historical dominance of discourses (such as respecting somebody's "personal space") become "black boxed" —taken for granted and not examined. Michel Foucault (2002) famously suggests that these cultural practices are effects of "biopower", authority that reaches right into the very finest ways in which our bodies are controlled, resulting for example in blushing in private at an embarrassing memory, thought or reflection. Importantly, for Foucault, we have not "liberated" ourselves from power and authority, or do not lead a more enlightened life (not spitting in public taken as a more "developed" cultural position). Rather, patterns of control, domination and resistance change forms historically. Biopower—social production and control of bodily functions (including illness) —is always there, but expressions differ historically. At any one point historically, as "sovereign" power is exerted as authority and *reproduced* through institutional structures, so "capillary" power is also *produced* and runs through any system or any body, showing fine regulation. Further, as sovereign power is exerted through dominant discourses, so it may be resisted by a counter-movement.

While the capacity to sense, imagine, feel, talk, work, consume, form relationships and so on is available to us as birthright, how these capacities are realized then depends upon a prior (historical) condition of possibility. For example, beyond the biological fact that one senses, how, what and even where one senses are culturally determined through pre-existing structures (Corbin 2005). At an institutional level, such as medicine, patterns of sensing become historically determined habits remaining largely unexamined. They have a logic of course: this is how a physical examination is carried out, this is how bedside teaching is done. But that logic can grow to be counterproductive, such as the habit of interrupting patients too early in the consultation, or of talking "over", rather than with, patients.

Patterns of sensing can go through Kunhnian revolutions—historically rapid paradigmatic shifts in ways of practice and learning. For example, the introduction of simulation into teaching both clinical and communication skills has revolutionized the ways that medical students learn how to insert a urinary catheter or communicate bad news. But, as these modes of learning become habitual, so they begin to produce insensibilities. For example, students can simulate, or worse, dissimulate effective communication (Bleakley, Bligh and Browne 2011). Currently, as discussed earlier, students spend less time in bedside physical examination and more making sense of the results of tests and scans, potentially leading to overdiagnoses (Welch, Schwartz and Woloshin 2011) and depriving the student-patient relationship of the ritual of professional contact. Students' senses are dulled in the process because the opportunity to sharpen them is withdrawn through new forms of medical education. Typical habitual production of insensibilities includes objectifying the patient as cynicism is modelled amongst seasoned clinical educators. Let us look a little more closely at the dynamics of production of professional insensibilities.

Inattentional Blindness

In a seminal experiment, James Potchen (2006) asked radiologists to review standard cases as if for an examination and introduced chest X-rays but with the clavicle or collarbone removed. Sixty percent of those in the study failed to notice the missing clavicle, simply because that is not what they were focusing upon. That 40% of the radiologists did note the missing clavicle means that the radiologists would characteristically scan the entire X-ray prior to focusing on the specific part relevant to the diagnosis. However, the power of attention to the specific generally cuts out the meaning of the overall image, so that the majority did not see the obvious. Does this matter? Well, selective attention may lead to the doctor missing information that is vital to a correct diagnosis, and this may then result in a misdiagnosis. Many misdiagnoses do not lead to harm, but some do. Of medical errors that lead to unnecessary death or serious harm, it is estimated that between 10-15% are due to misdiagnoses (Sanders 2010).

Potchen's study used a standard "single slice" medical image. Contemporary radiology, however, deals with far more complex imagery such as hundreds of slices in a chest CT scan. You would expect that an expert scrolling through a stack of images might more easily avoid error. Further, not seeing something that should be there is not the same as being "blind" to something that is there but is missed (psychologists call this phenomenon "inattentional blindness"). Evidence shows that it is harder to note the absence of what should be there than to detect the presence of something. A more striking and sophisticated recent experiment by Trafton Drew, Melissa Võ and Jeremy Wolfe (2013), at the Visual Attention Laboratory of Harvard Medical School, again shows that experts making visual diagnostic judgements are highly selective in their attention and perception. These researchers changed the conditions of Potchen's study by providing multiple images and introducing something which was plainly in the image but could be missed through focused attention.

That experts in visual acuity in medicine (primarily radiologists, pathologists and dermatologists) use selective attention in making standard expert judgements is something we already knew, but the results of Drew, Yo and Wolfe's experiments raise to awareness the implications of such selective attention for foreclosing on clinical reasoning, or making a hasty diagnostic judgement. The authors asked twenty-four expert radiologists to perform a standard and familiar lung-nodule detection on a standard X-ray. They scrolled through stacks of five chest CTs looking for evidence of nodules, that appear as light circles. Typically, a stack contains 100 to 500 slices. In the final of the five stacks, a large image of a gorilla was introduced. This stack contained 239 slices. The gorilla faded in and out of perception across five 2mm-thick slices within this stack. At the size of a matchbook, the image of the gorilla was 48 times the size of the nodule and was inserted in the last case presented.

Twenty out of twenty-four (83%) of the radiologists did not see the gorilla, although eye tracking showed that they had looked directly at the location of the gorilla—again showing "inattentional blindness". All the radiologists saw the gorilla clearly when it was pointed out to them. A non-medical control group was set up. These twenty-five individuals were trained to see the lung nodules. None of them saw the gorilla and this group, as expected, showed poor recognition of the lung nodules. However, this confirms that novices, who are looking "harder" than experts or in a sense straining their attention, also showed selective attention. A naïve group of twelve observers was shown a movie with the frames of the movie corresponding to slices of the stack, so that the gorilla was plainly evident on some of the frames. Eighty-eight per cent of this group was able to see the gorilla, showing that it was plainly visible also to the other two groups, but not "seen". This experiment also shows the phenomenon of "satisfaction of search". When what is expected is seen, the search is discontinued. This is an example of premature closure, and is one of the main causes of misdiagnoses.

The authors (Drew, Võ and Wolfe 2013, 5) conclude that

> Even this high level of expertise does not immunize individuals against inherent limitations of human attention and perception. Researchers should seek better understanding of these limits, so that medical and other man-made (sic) search tasks could be designed in ways that reduce the consequences of these limitations.

But there is another way—why not educate the perceptual or sensory acuity of doctors and healthcare professionals generally as core activity? Who better to do this than artists and humanities scholars—visual artists working with medical students and doctors to improve visual acumen; writers working to improve narrative intelligence; and actors and performance artists working to improve communication performance and management of identity? Indeed, this collaborative model can be extended to perfumier and oenophile (wine taster) educating the smell and taste of medical students (a successful and longstanding 4th year special study unit at Peninsula Medical School, UK).

Of course, in some areas, such as the use of actor-patients (introduced by Howard Barrows in 1963 at the University of Southern California), we might say that such actors have long taught performance to medical students and even assessed such performance. However, medical educators have managed to turn this opportunity into production of insensibility through an insistence upon standardizing actor patient-student interactions for the sake of fairness in assessment. No patient is “standard” —this is a form of objectification. Before moving on to recommend how, for example, visual artists and doctors might work together to create a new kind of pedagogy within medical education, we need, first, to thoroughly understand the reasons why such a pedagogical intervention is needed at all.

The Social Organization of Perception

The German literary critic, social theorist and philosopher Walter Benjamin (1968) first described pre-forming of the sensible in the early 1930s, where “the manner in which human sense perception is organised, the medium in which it is accomplished, is determined not only by nature but by historical circumstances as well”. The fact and consequences of perception includes the field of aesthetics. At root, aesthetics simply means “sense impression”. How perceptions are pre-organized through historical discourses is, however, a matter of power or politics. Benjamin thus initiated an important dialogue between aesthetics and politics.

The French philosopher Jacques Rancière is the primary contemporary exponent of Benjamin’s idea of the socio-historical pre-forming of perception (Deranty 2010; Bowman and Stamp 2011). Rancière adapts Karl Marx’s original insight concerning inequalities not only in the distribution of material wealth, but also in the distribution of the immaterial such as sensible and emotional capital. This is often referred to as the production and distribution of “knowledge capital” in a “knowledge economy”. Medicine produces, for consumption by patients and doctors, a range of material goods such as hospital buildings, ambulances, surgical instruments and pharmaceuticals. However, medical education deals largely with immaterial capital such as knowledge, practices and values, where the economy in which medicine works is largely that of talk and performance. How then is the collective capital of knowledge, practices and values distributed in medicine? Are there blatant inequalities in distribution and is “counter-capital” produced that is counter-productive to effective medical practice?

The Meeting of Aesthetics and Politics in the Distribution of the Sensible

Benjamin and Rancière, like many of Rancière's contemporaries in French postwar intellectual life in particular, have adapted Marx's legacy to explore contemporary social existence. Marx's main concern, in a rapidly industrializing world, was with how capital produced by factories (raw goods and their cash equivalent) would be distributed; and with who owned the means of production (factories, machinery, raw materials). Just as labour had been exploited through slavery to harvest raw materials such as sugar, or to dig metals from mines, so labour was exploited in factories or steelworks in refining the sugar or turning the metal into ingots. The owners of the means of production (capitalists) would cream off the major part of profit for themselves and exploit the workers by paying low wages, treating them as mechanical parts in a production process and threatening that they could readily be replaced if they rebelled. Workers were treated as dispensable objects or as units in production, stripping them of sensibility.

Marx's socialism promised to fundamentally re-organize the industrial process to give workers shares in the means of production such as factories, and to not exploit their labour but provide them with fair remuneration. Profits would be ploughed back to improve work conditions and living standards in a re-distribution of wealth. What, however, of a post-industrial world in which consumption of the immaterial (Gorz 2010)—ideas, symbols, education, advertising, entertainment and so on—is more important than the production and consumption of material goods such as televisions and cars? Post-Marxist analyses have taken Marx's ideas into the realms of the immaterial world by treating experiences such as human emotions or affect and human sensibility, or aesthetic responses and cultural taste, as capital open to manipulation by vested interests. For example, what we consider to be aesthetic "choices" in life, such as our manners, the clothes we wear, the colours of our cars, the art, or the music, cinema and television we enjoy, are manipulated by vested interests. Control over production and consumption of goods is paralleled by control over production and consumption of symbols, signs and knowledge such as entertainment, education and psychological therapies.

Where Marx focused on the fair distribution of material wealth and the ethical use of labour, Rancière considers the fair distribution of aesthetic and emotional capital and ethical use of aesthetic and emotional labour. Rancière notes that the "sensible" in life—what is worth noticing and appreciating and the processes by which sensing, noting and appreciating are socially legitimated—does not simply occur as a transparent or natural process. Rather, what is considered worth noticing and, more importantly, who is given the privilege to notice and appreciate, is determined socially. There is a process through which the sensible and sensibility are apportioned and applied that is fundamentally unfair or shows inequalities. Some (many) are considered insensible, or are denied participation in legitimate judgements about what is worthwhile noticing and appreciating. Aesthetics, or sense impressions, the basis for perception and appreciation, form a value system, but a dominant minority decides what these values shall be. This minority also further decides that some members of society shall be insensible, kept ignorant in terms of sensitivity and sensibility, implying that these members of society have blunt affect. The majority—who are left insensible—are the underprivileged, the poor and the disaffected (Vollman 2007), but in professions such as medicine this group includes those low on the hierarchy, primarily medical students. Aesthetics is then closely tied to politics—what shall be judged worthwhile to notice is inseparable from power. What is worth noticing (and requires close noticing) in medicine is symptom expression and this is often at the expense of noticing the person who expresses the symptom(s) and the contexts in which symptom expression occurs.

Rancière (2010, 36; 2013, ix) describes a historical transformation of the forms of sensible experience or "ways of perceiving and being affected". Aesthetics is described as a "mode of intelligibility" through "reconfiguration of experience". Again, we do not experience "raw" or directly, rather our perceptions are first formed, shaped and refined socially (and such social engineering is necessarily a political forming); and second, perceptions are adjusted through forms of education, themselves subject to the relationships between power (politics), knowledge and sensing. This leads to "ways…of being affected", in which persons, groups, societies and even cultures might be sidelined or conceived as "insensible" as they are denied participation in sensibility (Panagia 2010). Again, this can range from a privileged group deciding on what constitutes legitimate "art", "humanities" or "education" on behalf of excluded groups, to medical students as uninitiated "novices" being denied access to medicine proper until certain initiations have occurred and a level of expertise has been demonstrated. The sensible (again, the aesthetic realm) is first partitioned or parcelled off, and then apportioned or distributed (the realm of power). However, such partitioning and distribution, once raised to awareness, can be resisted. A major role for a radical and critical medical education is to show how redistribution of the sensible may be achieved through resistance, and primary media for such distribution are the arts and humanities within medicine and medical education—as primary forms of the medical humanities.

The "Police", "Politics" and "Dissensus"

Rancière (2006, 2010) suggests that power affecting the partition and distribution of the sensible operates through two channels: "the police" and "politics". The functions of "the police" (a general descriptor and metaphor for legitimized authority and control in a society) are (i) to fill a potential void ("move along, there's nothing for you to see here"), and (ii) to deny "supplement" (there may be another way of thinking about this, or of acting on that thought). Again, by "the police" Rancière does not mean just the police force. Rather, it is a general term for a legitimate authority's structuring of the sensible that distributes this capital selectively.

Rancière insists that the essence of the police does not rest in oppression, repression or control. Rather, "the police", as dominant and legitimate institutional practices, represent the privileged way of distributing the sensible. Just as wealth is distributed according to privilege—and then, in Marx's critique, reinforces inequalities—so the sensible (what is sensed and how it is sensed) is distributed through prior power structures. Again, perceptions, as modes of participation in the world, are contingent upon prior historical conditions. What shall be sensed and how it shall be sensed are pre-patterned.

"Politics", on the other hand, is a form of resistance to the police. Politics describes any intervention that attempts to redistribute the sensible, or to uncover the "black boxes" that insensibility produces—habitual practices that normally remain unexamined. Most importantly, politics gives a voice (subjectivity) to those who are normally excluded from participating in deciding how the sensible shall be distributed (again, the poor, the underprivileged, or those lowest on the hierarchy such as medical students in a medical culture). The process through which politics is mobilized as a redistribution of the sensible is "dissensus" (Rancière 2010). As Rockhill (2006, 85) suggests: "A dissensus is not a quarrel over personal interests or opinions. It is a political process that resists juridical litigation and creates a fissure in the sensible order by confronting the established framework of perception, thought, and action with the 'inadmissible', i.e. a political subject".

By a "political subject", Rockhill means a politicized person—someone who has seen through the processes by which sensibility capital is unfairly distributed or withheld, or, conversely, insensibility is produced. The politicized subject acts in resistance to such dominance.

This suggests that medical students and junior doctors can (or should) be politicized as well as aestheticized through medical education, gaining a legitimate identity as an active rather than passive learner and an authentic voice in their medical education. Patients and “other” healthcare practitioners should become part of this process of dissensus.

Pre-determination of what and how one shall engage with the world perceptually is of two kinds: first, separation and exclusion; and second, allowance of participation. Thus, says Rancière, “what is visible and what not” and “what can be heard and what cannot” is not an issue of persons naively entering the world and perceiving in a “raw” state, but rather the consequences of a set of preconditions that already shape perception. When “the police” say, “move along, there’s nothing for you to see here”, a “partition of the sensible” occurs that “is characterized by the absence of void and of supplement”. Occupations and places are already pre-determined such that there is no place for a void or doubt, uncertainty and ambiguity. Thus, *this is how a doctor shall perceive* (as in clinical judgement) is a matter of the distribution of the sensible through the efforts of “the police”—as those at the top of the medical education hierarchy in any local context (the chief clinical teachers).

The practice of “policing” is one of legitimating “what is” by repressing “what is not”, or what is *possible.* In contrast, the essence of “politics” is to reveal what is possible, through engagement with the ambiguous and uncertain. Politics again “is an intervention in the visible and the sayable” (Rancière 2010, 37) to redistribute sensibility. In essence, this is to change the conditions of possibility for sensing. Again, Rancière (2010) terms this “dissensus”—a form of resistance against the police. Dissensus (Panagea 2010) is a dissent from inequality and insensibility—the latter not only referring to how or what may be encompassed by the senses, noticed or discriminated, but, crucially, *an inability to be sensed, noticed or accounted for*. Of course, this “inability” is not an issue of agency, of wishing or choosing to be able to be noticed, but one of structure—of marginalization, exclusion and ineligibility.

If we take the example of the “birth” of democracy in fifth-century BC Athens—women and slaves were not part of this democratic experiment. They were “policed” as unsuitable for political involvement and then stripped of the opportunity to experience through the senses what men could. The distribution of the sensible was unequal. If this example is transposed to modern medicine, the conditions of possibility for sense experiences are highly regulated or policed by an elite authority of consultants or experts. What presents itself to sense experience in medical education is then preconfigured by this historical tradition (also, a male gendered body of expertise). Indeed, the sensible is ill-distributed where what is traditionally valued is the expertise of the autonomous individual—the heroic figure or the rogue diagnostician, caricatured in the most successful of all television medical dramas, *House, M.D.*, starring Hugh Laurie.

The distribution of the sensible can be equated with delimitation (drawing of boundary) of spaces and times and of the visible and invisible, as Michel Foucault (1989) traces in *The Birth of the Clinic*, where certain historical conventions apply such as the tight, focused case presentation (time) in the setting of the clinic (space) determining what can and cannot be said and performed. In medical education, patients are objectified as "cases" presented crisply and concisely within a limited time, where the "chief complaint" overshadows the "chief concern" (Schleifer and Vannatta 2013). This distribution of the sensible can again be read as production of the insensible, adding to the historical tradition of the bluntness, literal stance and materiality of the medical culture, with its suspicion towards the intellectual, the baroque, and the tender-minded.

Further, the clinic legitimizes what is not permissible in ordinary discourse, such as intimate examinations necessary for diagnosis and treatment. Here, the patient is again potentially rendered insensible. But such intimate interactions are complex. While the senses are focused and channelled for diagnostic acumen, a parallel insensibility is produced linked to ethical and professional behaviour, in which "normal" responses of sexual arousal, curiosity and disgust are suspended or dulled, while ethical boundaries are sharpened. In communication, professional "empathy" can be seen to be a result of the regulated balance between the sensible and the insensible in terms of ordinary human compassion being balanced by professional distance. The problem, again, is that historically the dominant discourse has been biased towards the—in relational terms—insensible, where empathy decline and moral erosion occur.

Rancière's model then accounts not only for how medical students' learning is pre-formed through an historically established tight distribution of the sensible, but also accounts for why medical students and junior doctors do not have an authentic "voice" in the practices of clinical learning. While pedagogies appear to become outwardly more "student-centred" and medical practices more "patient-centred", this does not necessarily disrupt the underlying structure of the distribution of the sensible, where forms of perception (aesthetics) and modes of relations (politics) resist redistribution shaped by equity (fairness and justice) and equality of opportunity.

Of course, medical students and junior doctors are novices learning clinical expertise from senior doctors and the gradual accrual by novices of expert clinical practice and knowledge offers a legitimate and standard form of appropriate distribution of sensibility capital. This is not what I am questioning or critiquing. Rather, my focus is on the supposed pedagogical expertise of clinical experts in promoting accelerated learning, student- and patient-centredness and professionalism and inter-professionalism. And, more importantly, on how democratic practices stemming potential empathy decline, moral erosion and self-insight and self-care (reflexivity) can lessen production of insensibility and insensitivity. To return to earlier points in this chapter, forms of "inattentional blindness" are endemic to medical education, as are resistances to democratic structures. Medical students gain identities as doctors through socialization into these skewed forms of the distribution of the sensible. Enlightened medical educationists should be applauded for their work in developing student-centred learning for patient-centred practice, but they are constantly working against the grain of the institutional and structural conditions of the production and reproduction of insensibility in medicine.

Tampering with this system will not change it. In order to democratize the processes of production and distribution of the capital of sensibility and sensitivity, the system of medical education needs root and branch changes. Dissensus, or dissent, requires a fundamental redistribution of the sensible. For example, wholesale introduction of generative medical humanities in medical education requires a revolution in medical education similar to that of Abraham Flexner's reforms of 1910 in North American medical education (Cooke, Irby and O"Brien 2010; Bleakley, Bligh and Browne 2011). However, as Rancière himself points out, dissensus is a slow and permeating process and not an overnight radicalization of practices.

The Re-Distribution of the Sensible Through a New Medical Education That Draws on the Medical Humanities

So what does Rancière's model tell us about the value of the medical humanities in medical education? Rancière insists that art's (and the humanities') function is to change or repair, through redistribution, the sensible fabric of the world. The arts and humanities make us re-think our lives, to look and think again, to think against the grain. The medical humanities do this for medicine—redistributing the sensible fabric of medical practice to make medical students and doctors think again.

Medical humanities interventions in medical education set out to—often disruptively—change the perception of students but also to politicize them, forming an identity of resistance (Weiss 2005). To dwell on the process of dissensus, let us equate Rancière's "the police" with a scientific medicine that is sceptical of the value of the medical humanities. Redistribution of the sensible is denied through design and implementation of a curriculum that excludes the arts and humanities and produces insensibility. Further, the burden of proof of the value of the medical humanities is placed on the shoulders of its protagonists rather than sceptics having to demonstrate the value of their scepticism. Again, the medical humanities can offer a medium for resistance or dissensus, inviting a (re)distribution of the sensible as a dual political and aesthetic gesture. This gesture counters the production and reproduction of the insensible through medical education.

To draw on Rancière's example, "the police" do not interpellate (demand an explanation and give an identity to) demonstrators, but, cleverly, refuse to offer an identity to demonstrators simply by breaking up the demonstration ("there's nothing for you here, please move on"). By not recognizing the medical humanities through moving the demonstration (resistance) on, sceptics treat proponents in the same way as the men in the Athenian democratic experiment treated women and slaves—as non-citizens or barbarians. To the sceptics, the medical humanities are, literally, a "non-sense" as distribution of sensibility is refused and insensibility is produced. Dissensus challenges such a partition and distribution of the sensible. This political intervention makes what was unseen visible and renders what was merely noise as speech. Dissensus challenges the notion that students do not have a voice in medicine until they have gained requisite technical expertise (actually, they may be highly capable morally, ethically and in communication and this may show in challenging perceived unethical practices of seniors). Juniors may well practice the art of medicine as well as, or better than, more cynical and hardened seniors, even if their applied clinical science and their development of pattern recognition diagnoses (based on exposure to patients) are still undeveloped. Historically, the Flexnerian legacy has deprived medical students of the early clinical experience that may accelerate learning clinical judgement because it insists on first forming the identity of "scientist". This deprivation is a form of production of insensibility as opportunities for early forming of pattern recognition are frustrated.

Rancière (2010, 38) says that dissensus is "not a confrontation between interests or opinions" but rather "the demonstration (*manifestation*) of a gap in the sensible itself". What Rancière refers to as a "gap in the sensible" I refer to as production of insensibility (either conscious or unintended). Importantly, here is the creation of an identity—as a humane practitioner who has acquired a slice of the sensible by speaking out against its repression. Again, this revolution is not an overnight coup, but a slow process of realization of the power of the medical humanities as a medium through which redistribution of the sensible is possible. When Rancière (2010, 92) says politics and "the police", respectively, refer to "two ways of framing a sensory space, of seeing or not seeing common objects in it, of hearing or not hearing in it subjects that designate them or reason in their relation" we can apply this directly to the doctor's relation to her patients and colleagues. This is not seen as a revelation, but rather reclamation, of what is suppressed by "the police" in terms of a denial of democratic distribution of the sensible. "First, do no harm" must be turned back on medical culture itself and its practitioners as an act of reflexive inquiry, a means of treating medicine's own maladies.

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CHAPTER TWO

"MY WEEK WITH JEFF": FOSTERING EMOTIONAL WELLBEING AND EMPATHY IN MEDICAL STUDENTS THROUGH CREATIVE WRITING

A CASE STUDY

ANNE TAYLOR AND ALED PICTON

In his book *Do No Harm*, neurosurgeon Henry Marsh speaks candidly about the challenges of being a doctor. Much of what happens in hospitals he says is "a matter of luck, both good and bad; success and failure are often out of the doctor's control" (Marsh 2014, ix). "I do not want to undermine public confidence in brain surgeons or, for that matter, the medical profession, but I hope that this ...will help people understand the difficulties, so often of a human rather than a technical nature—that doctors face" (ibid., x). While patients may choose to remain oblivious to the unpredictable nature of medical practice clinicians cannot avoid it. This does not mean that doctors find it easy to tolerate uncertainty, but evidence would suggest that those who acknowledge it and cope with it make better more empathic doctors (Bleakley 2014). How then can medical schools face the challenge of equipping trainee doctors with not only the technical expertise and good communication skills but with the "difficulties of a human nature", the lack of control, that Marsh describes?

The daily emotional challenges facing medical students should not be underestimated. Research has shown that fear of making mistakes, a demanding curriculum, time pressure and sleep loss, can result in a decline in patient empathy that often sets in during the third year of medical training (Hojat et al. 2009, Batt-Rawden et al. 2013). A growing number of medical schools internationally are integrating the arts and humanities in their curriculum in a bid to educate for "humane" medicine and provide a counterweight to reductive biomedical science with some evidence that this can halt the decline in empathy and promote emotional wellbeing of student doctors. Putting medical humanities at the heart of the curriculum can counter the pervading authoritarian culture in medicine and help trainee doctors to “create, and debate, uncertainty and ambiguity” (Bleakley 2014, 27).

This essay will explore the impact of a creative writing group on the personal and professional development of student doctors. The authors, Anne Taylor, the group’s facilitator and Dr Aled Picton, a student participant, will reflect on existing research and experiences of doctors, educators and facilitators who have used creative and reflective writing with medical students and explore the impact of a small writing group which was run three times over three years with fourth year medical students at the Peninsula Medical School in Truro, Cornwall. They will draw on their own reflections of the group and writing process together with those of student participants and examples of their poetry and prose to suggest that creative writing groups can benefit students in a number of ways; affording them a means of offloading stress and dealing with emotional challenges while providing a secure and safe reflexive space in which to “play with words”, wrestle with a variety of perspectives and grapple with uncertainty, something which has the potential to engender and restore empathy.

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“Writing is a form of therapy; sometimes I wonder how all those who do not write, compose or paint can manage to escape the madness, melancholia, the panic and fear which is inherent in a human situation”, said the author Graham Greene (1999, 7). Writing has long been recognized as a healing process for the writer but perhaps doctors have an added imperative to use it to make sense of the world. “The expressive urge is particularly pronounced in those who practice medicine...It’s like being a soldier. You’ve seen great and terrible things”, said doctor and novelist, Ethan Canin.

Creative writing and storytelling may have a benefit that goes beyond the physician’s self-development. Rita Charon, one of the pioneers of narrative medicine, an interdisciplinary study of literature and reflective writing, which promotes the importance of narrative understanding for healthcare providers, has put “narrative writing” at the centre of her practice believing it to have granted her access to knowledge of her patients “that would otherwise have remained out of reach” (Charon 2001, 84). She believes that teaching medical students to “bear witness” to patients and hearing their stories is fundamental to improved patient care (Charon 2006, 177).

A number of medical educators have used reflective writing and poetry with students and become advocates of the power of writing, arguing that the creative process and written articulation of new perspectives can not only improve empathy but also help students to deal with challenging situations. Johanna Shapiro, Deborah Kasman and Audrey Shafer drew on their own experiences of using a range of writing activities in academic medical settings and argue that a combination of writing, reading and listening:

> Can help learners become more comfortable with a reflective process that addresses loss of certainty, personal voice and others' voice, multiple perspectives, emotion, vulnerability, mindfulness and witnessing. All of these in turn can play a positive role in professional development, patient care and physician well-being. (Shapiro et al. 2006, 242)

Emergency physician and writer Jay Baruch sees a clear distinction between reflective writing for self-exploration and creative writing as a means of enhancing clinical acumen. The writer's imagination and craft and "sensitivities to story construction deserve a vital space in medical education" he says. Thinking like a creative writer and writing stories, he argues, provides the tools for clinical excellence and empathy (Baruch 2013, 459). Similarly, an evaluation of a poetry workshop, which encouraged students to do "poetry for poetry's sake" with a professional poet, found it "enhanced skills of observation, heightened awareness of the effect of language and fostered deep reflection". Poet Ann Kelly found that "by focusing on the skill of deep observation, especially the observation of what is often taken for granted (such as everyday events in our own life and the lives of others) students develop their power of imagination and, ultimately, empathy" (Collett and McLachlan 2006, 5).

Gillie Bolton, however, has harnessed reflective practice to the explorative and expressive power of creative writing. Her practice, much of which has involved work with health practitioners, has found using this in small group work supportive and educative where writing becomes a means of reflection and something for discussion in a supportive environment, allowing doctors to reflect and evaluate on emotional responses to everyday practice and relieve stress.

> Writing or telling narratives of experience is extremely important in the training of doctors. It enables clinicians to examine their practice critically from a wide perspective, and to increase their understanding and empathy by exploring a range of experience, knowledge, and emotions other than their own…We are our stories; writing and rewriting them keeps us alert, alive, and flexible. Writing and sharing stories and poems keeps us

> questioning: questioning medical practice, our patients, ourselves. (Bolton 1999, 243-5)

The creative writing group in Truro borrowed from the work of Gillie Bolton and was designed for personal and professional development, a strand of therapeutic writing that she has helped to pioneer in the UK. This meant that the main focus, the first imperative, was on using creative writing as a means of reflection and exploration. There are a growing number of practitioners in the field of therapeutic writing, the practice of which is complicated by the use of a range of terminology.Writing for personal and professional development, writing for wellbeing, therapeutic writing, expressive and reflective writing, poetry therapy are all used, sometimes interchangeably, to describe a field of work with facilitators coming from a range of professional backgrounds—writers, teachers, counsellors and psychotherapists—and who are represented by Lapidus (the Association for Literary Arts in Personal Development). The defining features of this work are "writing practices where creative processes and expression and reflection are prioritised over writing as a finished product or artefact" (Hamilton 2013, 147) and it is this definition which underpinned the creative writing group at Truro.

The defining feature of the writing group was to provide a space for students to play and experiment with writing and words, using writing to tap into thoughts, feelings and memories, before creating and crafting a piece of work to share with a small audience. This was not a creative writing group where work was critiqued on its literary merit. Putting the focus on process and play ensured that writing took place in a non-judgmental context and allowed students room for experimentation. Our mantra was that no writing was wrong writing. This meant that material which was potentially sensitive could be shared with an audience of like-minded peers, without fear of criticism. This made the idea of the group less intimidating for the students, some of whom were unsure of their creative writing skills. There was a will to craft and redraft pieces into meaningful poems and prose for a wider audience, and this redrafting in itself was found to be a therapeutic part of the process, often giving the feeling of control over challenging thoughts and feelings but it came secondary to the initial value/ power of writing for self-exploration and development.

The Truro Group

The writing group was facilitated by Anne Taylor, senior lecturer in the School of Writing and Journalism at Falmouth University, a writer and journalist with a special interest in writing for personal development. Three groups of four or five students ran in consecutive years involving a total of thirteen students as part of a series of compulsory medical humanities Special Study Units (SSUs), which have been at the heart of medical education since the Peninsula Medical School was born in 2000. (In 2013 the Peninsula College of Medicine and Dentistry was split into the Plymouth University Peninsula Schools of Medicine and Dentistry and the University of Exeter Medical School and the medical humanities SSUs are continuing.) The special study units have seen hundreds of students working with artists in their studios, participating in life drawing classes at Falmouth University, experimenting with poetry and creative writing or composing music. The philosophy is that being creative through art and writing is an opportunity to educate students’ senses and improve their diagnostic acumen and see medical practice from a different perspective. The special study units have been led by a number of providers—professional artists, writers and academics, many of them from outside the medical school.

Students who came to the sessions had specified their preference from a range of topics and were interested in taking part in the creative writing for personal development module. They were in general open to suggestion and eager to do well. A number of students were in the process of spending nine weeks with the oncology and palliative care teams on a demanding pathway which saw them encountering challenging diagnoses and prognoses with patients. We met five or six times over an eight-month period. The students weren’t directed to write specifically about their training or medical practice but most students did so, one using poetry as an escape from pressures of medical school and two of them as a means of exploring difficult childhood experiences, or own experiences of illness. The idea was to free up imagination, expose the liminal space for play and allow each student to develop their own interests and explore their own experiences.

Each two-hour session involved an hour of creative writing together followed by an hour of shared writing. The approach was flexible and intuitive and drew on journal writing techniques, poetry therapy, reflective practice and the work of other practitioners in the field, activities and ideas designed to prompt interest and allow students to take their writing and reflections in a direction of their choosing.

Core Activities

Freewriting / Flow Writing

Freewriting, sometimes flow or automatic writing, the process of writing for a few minutes without stopping and without attention paid to punctuation or grammar was a core activity practised every session. The technique has been shown to help people “move towards a freer and more spontaneous experience of creativity” (Creme and Hunt 2002, 151) and allow access to information that we may have “absorbed unwittingly” (Bolton 2011, 189). Students were often surprised by what they found on the page after taking part, suggesting the power of pen in accessing memories, feelings that sit in our subconscious, supporting the work. “The idea that writing involves finding out what one has to say in the process often comes as a considerable surprise to many people, particularly those new to writing” (Creme and Hunt ibid.). The experience of researchers in Bristol, where students practised creative writing as part of a medical humanities programme also suggests that freewriting seemed to work in “unlocking expressive potential” (Thompson et al. 2010).

Journal Keeping

The students were introduced to the value of “journaling” and encouraged to keep one to record their private thoughts, feelings and observations throughout the course (borrowing from the work of Adams 1990 and Thomson 2010). Some students took to using freewriting in their journal on a regular basis; others made use of suggested journal prompts like list writing and letters.

Creative Prompts

Each session involved some freewriting together and a range of writing activities. We used objects and postcards and poems as prompts, wrote letters from different perspectives, created a group poem after a tour around the hospital paying close attention, played with metaphors and on developing characters out of self (following an activity by Cheryl Moskowitz 2005). All activities were designed to inspire the imagination and prompt the creative process.

Crafting and Sharing

In their own time, in between sessions students were asked to craft a piece of prose or poetry and bring it to the following session for sharing. The only rule was that the piece of writing should not be more than a side of A4, to allow equal time for each participant. There was no suggestion that the work should be oriented around students’ medical school experience or practice. The second half of each session was dedicated to the sharing of work and to peer feedback and discussion. Responses and feedback on writing was encouraged but was carefully framed so that respondents would talk about how the writing made them feel and provide a prompt for discussion rather than being critiqued for its literary value.

Reflection on Process

To underpin the portfolio of creative writing that students developed, and as a requirement of their medical humanities special study unit, students were asked to write a 1,500 word reflective essay on the process of writing and to present their work and reflections to their peers at a conference. The reflective piece allowed students the opportunity to draw on research and thinking in the field and to inflect this into their own experiences. It is from these reflective essays that the following comments from students have been drawn.

Findings

The writing groups were an enjoyable and fulfilling experience for participants. All thirteen students had reflected on the benefits of writing and suggested that taking part in the writing groups had allowed them to explore and release emotions and see things from new perspectives; some added that they felt that this had made them more empathic to patients.

The act of writing itself was found to be cathartic and a means of acknowledging and exploring some challenging emotions. Freewriting in particular, helped with this: “I discovered that I did have something to say even when I didn’t think I had”, said one medical student. The students’ writing most often addressed experiences that they had found difficult—ranging from situations and incidents that they had witnessed in the hospital to personal experiences of illness and divorce. A number of them reflected in their essays that writing about these incidents had allowed them to address previously un-addressed emotions. One student who had experienced a chronic illness in her teens came through writing a series of poems about the experience to retrospectively "acknowledge the validity of my emotional response and express the anger bitterness and isolation I had felt".

Some students found it enough to write expressively about their experiences in the safety and privacy of their personal journals, others found that taking their writing a step further and crafting a poem or narrative had felt cathartic and allowed them to let go. Some of these experiences were kept private; others found value in sharing them with the group. As one student suggested:

> Writing in a journal so often and documenting my experiences, thoughts and feelings has been a beneficial and cathartic experience. The privacy has greatly appealed to me. I have been uninhibited and able to write about personal life experiences and the extremes of my emotions. The writing has been my pure truth and not adapted to suit others.

The majority of students wrote poetry rather than prose, although the choice was entirely up to them and it was suggested that it was this creative form in particular which helped them release emotions. One student used poetry as a means of recognising and releasing her anger while on the palliative care pathway.

> I found the poems extremely therapeutic to write and in some cases they helped me to address things that I wouldn't normally. I found myself venting about the unfair nature of disease and the anger I felt over the fact we are powerless to affect things like this.

Another found that writing a poem was an outlet allowing her to express and deal with her sense of guilt for not giving the patient the attention they deserved: "It wasn't until I wrote the poem that I realised how guilty I had felt about not empathising with their suffering". Writing about the event had allowed her to "reclaim" the missing empathy and prevent it from slipping away further.

As well as providing emotional release, taking part in the writing group allowed students to play and become more comfortable with uncertainty. By its nature, rather than its design, the writing group provided a reflexive space in which students could face and explore a number of "others" or alternative and sometimes dialogic perspectives. We would argue that this particular type of writing group, without rules and constraints—where the emphasis was on process rather than product—afforded the opportunity to play with numerous perspectives as described below.

Perspective from the Page—Facing Up

From the fresh perspective of the page, students were able to acknowledge and deal with some challenging feelings.

> There are things that are too difficult to express or too personal to say to someone else but through writing I am able to say them to myself. I am able to look at them from another perspective, from the words on the paper. This broadens my visual field and allows me a clear view of what I am truly experiencing.

Poems in particular provided a safe container for sometimes difficult emotions and a means of letting go. Seeing the words on the page aided this sense of release. Writing a poem about a chaotic and potentially traumatic event on a maternity ward allowed one student to deal with the unhelpful emotions that she had attached to it

> Putting it on paper felt like I was releasing it from myself and the perspective of the poem helped me distance myself from it.

Perspective of the Group—the Power of Sharing

Writing together in a group and sharing their work not only provided students with a safe space for play and mutual support, it also provided participants with new perspectives on their own work and feelings and on the contributions of others.

> Within the writing group we created an environment that felt safe and secure. I felt confident and willing to contribute and I had no fear of embarrassment or humiliation. This sharing of work gave me a better insight into the other members of the group. I was able to empathise with them when they discussed their work.

Another student was initially "nervous and hesitant" to share his writing but found that his confidence grew as a result of the sharing process: "The process of sharing work and receiving feedback has increased my self-esteem and I feel I am more able to engage in activities that may have previously made me feel uncomfortable".

> I would recommend this to any medical student interested in poetry as it gave me an insight into the lives of some of my peers and how people reflect on situations in different ways. Hearing some of the poetry also made me reflect on my own emotions and feelings about patients and

> difficult situations that we can often face in medicine. I wasn't aware of these feelings until I had heard some of these poems.

Another said: "The process of sharing work with a group of peers was a big contribution. While writing the poetry and prose was a learning process, sharing work with the peer group allowed me to receive different interpretations of my own work giving me new perspectives".

Patient Perspectives: Paying Close Attention

In the writing exercises in class, and through developing material for sharing, students were encouraged not only to explore their own feelings but also to develop the eye of a writer. The result was a portfolio of poems and prose that often centred on experiences in the ward. Close noticing—whatever the inspiration for it—was a by-product. One student wrote a story in the form of a poem about a man's sadness about not being able to go fishing with his son after his cancer diagnosis. He reflected that until he had started looking for stories he had been viewing patients as examples of "a phenomenon or complication".

> I had not viewed these patients as individuals…[and] had approached these patients with a lack of empathy. I am grateful of having the opportunity to reflect and write about the situation. I have subsequently developed as a medical student and person.

The writing group allowed students to experiment with language and metaphors in a way that was new to them. During one of the sessions, we played with finding new metaphors to counterbalance the dominant military metaphors in medicine. One student took this further and decided to observe how patients were describing their cancer. She wrote a series of haikus which helped develop her understanding of the patient perspective.

> The cancer clusters
> Fungus spores in my bones
> Which grow and grow
> Bald scalp and flat chest
>   Mirror reflects my sadness
>   Little pea is gone.
> Deep inside of me
> there is a monster lurking—
> I want it out

> I feel planted, calm
> the cancer clings like ivy
> I am an oak tree.

"I have not experienced cancer myself—to me it is an abstract concept," she said. "I repeatedly found myself asking 'what does it really feel like?' I gained a greater understanding of this by expanding on the language and metaphors supplied by patients".

Reflection on Process Itself—Another Layer

Throughout the special study unit, students were developing their own learning outcome as a means of reflecting on their experience of the medical humanities and of the creative writing group. This provided another reflexive dimension. They were encouraged to explore the research of those in the field of writing for personal and professional development and of facilitators working in the area. It also raised awareness of the potential power of creative writing for personal development by encouraging them to read around the subject and interpolate this with their own experience and work.

Reflexivity, Uncertainty and Empathy

> "[Reflexivity] is about being able to stay with personal uncertainty…and flexibility to consider changing deeply held ways of being." (Bolton 2010, 14)

Through careful facilitation, and a universal willingness on the part of participants to engage and support one another, the group had provided a safe space for creative play; a place where students could acknowledge the risk and uncertainty that Marsh describes above, and to explore and experiment with it on the page. The process had encouraged and allowed them to see and experience things from multiple perspectives (see above) and this had prompted reflexivity—the process of turning or reflecting back on the mind itself—which Bolton argues is an important means of allowing students to develop understanding of themselves and others.

> Reflexivity is finding strategies to question our own attitudes, thought processes, values, assumptions, prejudices and habitual actions, to strive to understand our complex roles in relation to others. (Ibid., 13)

Hunt and Sampson explain reflexivity as a constant dialogue: “It involves creating an internal space, distancing ourselves from ourselves, as it were, so that we are both ‘inside’ and ‘outside’ ourselves simultaneously and able to switch back and forth fluidly and playfully from one position to the other, giving ourselves up to the experience of ‘self as other’ whilst also retaining a grounding in our familiar sense of self” (Hunt and Sampson 2006, 4). Qualley, however, stresses the importance of “critical engagement” with an “other” in the reflexive process, but says that this other can be another self, a text or another person (Qualley 1997, 11). It is this which differentiates reflexivity from reflective practice.

The group and writing activities were an important reflexive space for students to enter into dialogue with the perspectives and others mentioned above. Above all, it was a place where students felt safe to play and experiment in a supportive environment where no writing was wrong writing. Bleakley and Marshall (2013) describe the medical humanities as a form of “*adult play*” and Baruch emphasises the importance of space where “The goal isn’t to make a construction but to be messy and to risk making mistakes” (Baruch ibid., 468).

Crème and Hunt have already summed up the potential of the group as a space for play by drawing on the theory of psychoanalytic therapist Donald Winnicott (1971). They argue that their creative writing workshops “provided safe, transitional spaces where the participants could play with, and mediate, a range of aspects of ‘inner’ and ‘outer worlds’” (Hunt & Crème 2002, 146). Indeed Bolton suggests that participants need to accept uncertainty to take part in creative writing workshops and describe this process as “a form of serious play” (Bolton 2010, 71).

By way of conclusion we use an example to show such reflexivity in action and Aled, one of the co-authors of this piece, will then reflect on his own experience of the writing group and of producing a poem, “My Week with Jeff”, from which this chapter takes its title. Through writing and sharing her poem, one student came to accept uncertainty through writing about an emotional clinical experience. While working on placement in general practice, she arrived at a care home with a GP to find the staff asking the doctor to sign a certificate in anticipation of a patient’s death. Rather than do this the GP carefully examined the patient, who appeared to be close to dying, and then started slowly spooning water into his mouth. This is one verse of a powerful poem that she wrote about the experience:

> Mouthful after mouthful the doctor delivers
> And an awkwardness fills the small space

The silence is louder than a drum roll
There will be no words here to save face.

This is what she reflected:

> It was the first time I felt bombarded by so many feelings in the clinical setting and needed to find a way to make sense of what I had experienced. There was sadness, anger, disbelief and even happiness. There was also gratitude, which is what I found myself feeling towards the doctor for identifying the patient's need for water. I felt admiration and inspiration too.

She added:

> I do believe that I wouldn't have been able to decipher my true and deepest feelings about this without writing it all down…Doctors are not expected to express certain feelings and sometimes I have felt the loss of identity because of this. This poem gave me the opportunity to stop hiding behind ideals. It let me express what I was feeling quite bluntly without experiencing too much guilt. In the past I would push aside some aspects of medicine that were unimportant or unchangeable—Now through writing I realise that there is always change to be made, even if it is just within me.

We hope that this case study may provide a model and some inspiration for similar work in medical education.

Dr Aled Picton: "My Week with Jeff"

Monday
You lie propped up in bed, jaundiced but smiling.
Your grasp is warm when we shake hands.
I meet your children, and together you tell me what brought you here.
You smile and talk about
knocking back pints of ale,
cigarettes in the merchant navy,
getting home to work on the garden.
I promise I'll be back tomorrow.

Tuesday
It's late and I'm tired. I almost don't come to see you.
Your name is missing from the screen.
I ask what ward you've moved to, and I'm met by whispers.
Your consultant is still in shock,
blunt
shutting the door of his office in my face.

Wednesday
I sit down with your notes.
In these scribbles and numbers, your last hours.

Thursday
You’re my case for the week, so I share your story.
I’m asked: “first and foremost, are you ok?”
I say that when I got home on Tuesday, I put sugar in my tea.
I’d never done that before.

Friday
Here you are again, still yellow,
this time lying limp on cold metal.
I hold your cancer in my hands, taking in the craggy weight of it.
We look down the dark tunnel of your arteries and find our answer.

They sew you back up.

Peeling off my gloves, I wash my hands of you.
But I won’t forget.

I participated in one of Anne’s creative writing groups in 2011/12, when I was a fourth-year Peninsula medical student. I am now in my second year of work as a junior doctor. During the six months of the creative writing group process, I spent a lot of my time in the hospital environment on the Oncology and Palliative Care pathway. During each pathway week, we would need to find a patient case for our “feedback” session. This would involve talking to a patient on the ward, examining them and then following their progress over the course of the week. Finally, we would present the case to a Consultant and explore the issues raised by it. “My Week with Jeff” was written about a patient I met during an Oncology pathway week.

The poem’s title is shared by our chapter. I feel that it represents how creative writing and sharing this in a supportive group environment helped me come to terms with an emotionally challenging experience. This was my first involvement with a patient’s death and I can remember all of the events described in the poem vividly, despite this being almost four years ago. I was keeping a journal at this time as part of the creative writing project, which helped me document my emotional responses at each point in the week and improve my self-awareness. Gathering all of these thoughts together, I chose to write the poem in a day by day format to reflect how the events unfolded.

My learning outcome for this project was to develop my understanding of different perspectives in medicine: my own and those of patients and other healthcare professionals. In this poem, I used a first-person narrative to communicate my perspective as a medical student, but I also tried to incorporate the patient's perspective. I feel that this project helped me to appreciate the range of different perspectives that shape each medical encounter.

When I met the patient in the Acute Medical Unit at Treliske Hospital, I spent at least half an hour chatting with him and his family. I felt that I built up a real rapport by getting to know him as a person rather than as a patient. This is reflected in the "Monday" section of the poem, which emphasises the patient's perspective and interests. Looking back at this experience, I now realise the luxury of time that we had as medical students and how this helped us build emotional connections with patients.

In my current role as a junior doctor, we are under constant time pressure to review multiple patients, many of whom can be acutely unwell. As a result, it is not always possible to forge such connections. However, as I have now learned, working as a doctor involves a balance of empathy and resilience. As a medical student, I was empathetic but had not yet fully developed any resilience skills or coping strategies—hence the emotional impact of this patient's sudden and unexpected death.

The sense of suddenness is what I wanted to convey in the second stanza of the poem. When I met the patient on Monday, he had been well in himself and stable medically. He underwent a routine ERCP (Endoscopic Retrograde Cholangiopancreatography) procedure to investigate a suspected pancreatic cancer on the Tuesday morning. Unfortunately, he died during the procedure. Arriving on the ward later that day to see him again, I was taken aback to learn that he had died. I went to ask his Consultant what had happened but he had neither the time nor the inclination to discuss the events.

Creative writing helped me reflect on why I found this experience so upsetting. A key aspect of the experience was sharing my work within the group. This proved to be a cathartic process: group discussion helped me to realise that it was the unexpected nature of the patient's death that I found difficult to cope with.

I asked to attend this patient's post mortem—this experience is described in the "Friday" stanza. This revealed a severely blocked coronary artery: evidence that he had died from a sudden heart attack. It also confirmed the likely diagnosis of pancreatic cancer. This cold, clinical experience contrasted starkly with meeting the patient earlier in the week.

However, it did help me to achieve some closure by ascertaining what had happened.

Looking back at these experiences, I can see that keeping a reflective journal and collating this content into a poem formed a documentation of my search for answers about what happened to this patient. I know that I may act differently now—with just a few years of work behind me I have developed more coping strategies and learned how to cope with patient deaths. Because it is based on contemporary journal entries, the poem accurately captures a specific flashpoint in my training. Using writing as a creative outlet helped me to recognise and express my emotional responses to this patient's journey.

Taking part in the creative writing project helped me to develop my reflective writing skills. This has been a good outlet when faced with other challenging circumstances as a medical student and a junior doctor. As an example of this, I went to Guatemala for a one-month elective hospital placement in 2012. During my time there, I wrote an online blog which helped me reflect on some of my experiences of working in a resource-poor environment. I felt more confident turning to writing as a method of exploration and self-expression from my experiences in the creative writing group.

Reflective writing is now an essential part of our revalidation and appraisal process as junior doctors. From my experience in this writing project, I feel that I am now able to pursue this in a meaningful manner that helps me as a practitioner.

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CHAPTER THREE

IN THE BLOOD: MAPPING NARRATIVE CIRCULATION IN ONLINE LEUKAEMIA NETWORKS

JULIA KENNEDY

On a late afternoon in March 2011, I left work early to pick up the results of a blood test from my GP. Less than an hour later, I sat in his consulting room absorbing a diagnosis of chronic lymphocytic leukaemia. I was temporarily silenced by shock but as my voice slowly returned, key questions emerged about the disease and its likely impact on my future. These are the answers I got. Chronic Lymphocytic Leukaemia (hereafter CLL) is currently considered incurable. It is treatable however. Its progress varies widely. Some people might die of conditions related to their disease within 2-5 years, whilst others might live twenty years or more. There was no way of knowing where I personally would sit on the spectrum of disease progression. It is, I was told, regarded as a "good" cancer due its often slow progression, and relatively manageable symptom burden in the early stages.

Although still the most common form of adult leukaemia (accounting for approximately a third of all leukaemias diagnosed in the UK), CLL remains relatively rare with an annual incidence in the UK of about 3.7 cases per 100,000 (Cancer Research 2011). Not all GPs are familiar with treating patients with the condition, and patients with a suspected diagnosis of CLL will be referred to a haematology consultant. My own GP was unable to answer the fundamental questions I asked as I struggled to absorb the implications of a shockingly elevated white cell count and the words "probable CLL" printed on the test results he handed me that afternoon. Played out daily in clinics and GP surgeries across the land, these are the mundane moments that change lives forever. On the tails of lab reports such as this, the potential of imminent mortality comes shrieking into lives with all of its insistent, demanding questions. Its clamouring displaces everything. How long would I live? Would I need chemotherapy? What would life with CLL be *like*? My GP was sorry—he didn't know what this would mean for me. Acknowledging the dreadful paradox of so grave a diagnosis with so little information, he referred me to a haematologist, and advised me to go home and "*look it up on the internet*" in the meantime. Two mutually intertwined research projects began that day. The first, and most immediate, focused on the task of gaining the knowledge I needed to move forward and survive. Growing out of that came the second—a four-year doctoral exploration of narrative circulation in online CLL networks. That project is now approaching its end, and this paper is a version of one I presented at the Malady and Mortality Conference at Falmouth University in September 2013, outlining my aims and methodological foundations for the work.

Awaiting my Consultant appointment following the initial diagnosis, I followed my GP's orders with evangelical zeal, scanning the internet for all of the information I could find on CLL. I learned that it presents differently from other leukaemias. Most patients are fifty years old or older, usually male and often asymptomatic or mildly symptomatic when diagnosed, and most do not require immediate treatment. Indeed, some patients never require treatment, yet for others, an indolent phase evolves into disease progression indicated by deteriorating blood counts, increasing fatigue, frequent infections, and enlargement of the lymph nodes or spleen. When symptoms impact severely on quality of life, or become life-threatening in their own right, treatment is advised. Chemoimmunotherapy (CIT) regimes have formed the "gold standard" of CLL treatment for over a decade now, improving outcomes for many on the previous standard chemotherapy.[1] A subset of patients with particularly favourable genetic profiles still find themselves in remission up to twelve years following their initial treatment, leading to hopeful speculation about the possibility of a "cure" in these cases. Only time will tell if that hope turns out to be more than speculative, and for a significant number of patients, remission remains temporary, with further treatment being required on relapse. Whatever the genetic profile of a patient, significant toxic side effects accrue from CIT, and those requiring repeat cycles see diminishing returns and increased impacts from toxicity. I learned that currently, the CLL world is buzzing with optimistic accounts of a brave new world of molecular treatments and even potential cures, many of which are rolling out from trial to market across the globe. I also learned (frustratingly as it later turned out when it transpired that my CLL was not of the indolent variety) that translation from pharmaceutical research and development to accessible prescription is a long-tail process rendering the discourses of hope and excitement chimerical for many currently suffering from CLL.

In that early process of researching CLL online I was struck by the heterogeneous nature of a disease that kills some patients within months from diagnosis, leaves others alive and relatively well for decades, and presents a range of potential outcomes between these extremes. It seemed then (as it does now) that uncertainty is the only current certainty of diagnosis with this disease, and inconsistencies in levels of information given to patients, as well as approaches and access to prognostic testing and treatment are apparent. One certainty, however, was the drive among some CLL patients for collaborative exchange of information and experience. This was evidenced by the broad range of support sites, blogs, and user-generated content in relation to the disease, dealing not just in biographical narratives, but very clearly engaged with a broad range of information and discourses contingent on disease experience.

Although researchers are beginning to explore online communication and support in chronic illness generally (Fox and Purcell 2010), chronic blood cancer experiences are woefully under-represented. Given that CLL accounts for around a third of all leukaemias diagnosed in the UK (8,300 altogether in 2009),[2] this represents a significant gap in the literature.[3] Evans et al. (2011) outline the negative psychological impacts of living with this "incurable, invisible, and inconclusive" disease, recommending widespread recognition of patient requirements for ongoing information (Evans et al. 2011, 1). No work has been published to date on how this group mobilizes the internet to address their information and support needs, nor what can be learned from that about both living with CLL and the internet cultures of disease generally. Yet I was discovering that a vibrant exchange of knowledge and experience and the mechanisms that enable it remain largely hidden away in semi-closed communities online.[4] This work sets out to bring some of that to the surface where its potential range of impact might be broadened.

Key CLL support sites functioning as hubs within complex networks connect to a variety of circulating narrative enactments of CLL. This is a network peopled with many different actors—human and non-human—those with CLL and those without, and key among them is Tom Ferguson's[5] (2007) vision of the informed, connected and empowered "e-patient" at work, tapping into and sharing a wealth of information from the complex hard science of a disease poised at a crossroads of biomedical understanding, to the daily effects of living with a cancer whose sufferers record exceptionally low emotional well-being (Shanafelt et al. 2007).

In an evolving model of medical citizenship where digital cultures are beginning to re-shape traditional dualistic roles of knowledge exchange between patients and their clinicians,[6] virtual narrative accounts of disease experience play a significant role in peer-to-peer and professional communication relationships. We are witnessing a powerful revolution in the hegemony of medical knowledge production/consumption, at the heart of which sits Ferguson's "well-wired patient" (Ferguson 2007). Patient-centredness is reconfigured as patient-connectedness, and both patients and clinicians alike must work on reconstructing traditional identities. Part of that task involves understanding the complex networks that the experiences of disease are meshed into and that, arguably, the internet has made more immediately visible and accessible. Online narratives speak of multiple disease experiences from multiple actors and their traces and intersections can be effectively mapped.

Patient narratives of CLL online are networked into a complex mesh of social, political, economic, and cultural threads—connected by global systems of information exchange, yet grounded in local contexts of healthcare delivery, disease management, and personal experience. As my own story became enmeshed in these complex networks, I began to get a sense of the many actors involved in bringing a disease into being: connecting our blood cells to lab technologies and scientific research; relating clinical treatment decisions to the pharmaceutical industry, its investors and regulators; linking governance of local healthcare delivery to political economies; relating all of these aspects (and more) of our disease to the information technology that enables their (and our) various narratives to be shared; and acknowledging the cultural attitudes that frame the stories we tell each other and ourselves about disease.

The production and study of illness narratives (or pathographies) is a rich scholarly field in its own right pre-dating internet communications by many years. The varied montages of narrative objects circulating in online health networks, however, defy the kind of generic certainties required to pin down what we define as "illness narratives" in the traditional literary sense (biographies, short stories, poems, journals and so on). Time spent in digital narrative networks also makes it clear that digital pathographies begin to defy traditional binary models of "evidence-based" *versus* "narrative-based" medicine in which the latter is located as demonstrative acts of individual agency set against the de-personalizing institutional medical gaze of the former (Bell 1999; Langellier 2001; Riessman 2002). With their ongoing and unfinished nature, resistant to generic containment, digital illness narratives become an "amalgam of literary and non-literary forms, including autobiography or biography, journal, and medical chart" (McLellan 1997, 100-101).[7] In this paper, I suggest that we add a range of alternative narrative forms circulating online to the amalgam. These include (although not exhaustively) research papers, conference proceedings, pharmaceutical industry press releases, policy documents, medical education sites, news, social media, and a range of popular cultural texts. In tracing the intersections of such varied circulating narratives with individual CLL pathographies accessed in online support communities and survey work, I offer a methodology for mapping evolving digital health narratives which, avowedly collaborative and hypertextual in nature, often present as an accretion of multiple practices and motivations. My aim here is not to produce a schism or clearly defined moment of rupture between traditional illness narrative approaches and digital forms. Instead, I want to offer a view of digital pathographies as narrative forms evolving in line with changing technocultures, at once drawing on, and contributing to changing relationships between medical (and para-medical) professionals and patients, and broadly contextualized by a re-consideration of narrative form in an information culture.

Walter Benjamin has argued that "narrative could not survive the moment of information" (1992, 73-89). This "moment of information" can be read through the rise of database culture which, it is suggested, can in itself be read as symbolic of life in Lyotard's "computerized society" (1979). "Database" in this context is seen by Manovich as an organizational cultural framework in a postmodern vacuum of grand narratives into which has rushed "an endless and unstructured collection of images, texts, and other data records" (Manovich 1998, 2). The urge to develop a poetic, aesthetic and ethical framework for the database appears strong though (ibid.). Narrative forms threatened on Benjamin's terms may evolve into new communicative practices that retain the imaginative alongside the informational, and that might lend themselves to less hierarchical modes of production, access and exchange.

Bassett (2007) suggests that information- pervasive new media forms operate as complex, multi-layered assemblies (both temporally and spatially) challenging traditional linear notions of narrative:

> Narrative, understood as an extensive arc constituted by a process of emplotment that both reaches back into the horizon of the event and forwards into the horizon of the reader, can make sense of these experiences through a form of assembly that is not retrospective but in process, not necessarily linear but rather expansive, and that is certainly open and indeed *generative.* (Bassett 2007, 3)

Narrative is presented here as "an intrinsic part of a new informational economy which becomes its material and which it holds and articulates" (Bassett 2007, 3). "*Which it holds and articulates*" is the important point here in relation to my own work. So, does the contemporary illness narrative encountered online demonstrate the ability to assemble the more informational narratives in the CLL network into its fabric in the expansive and generative way suggested by Bassett? I believe so, and through a process of mapping the connections and intersections of a range of circulating narratives online, this work sets out to test that hypothesis.

It is through my interest in the material effects of *multiple* narratives of a nominally singular disease coming together, that I draw for my methodological design on the ontological politics of disease proffered by scholars such as Annemarie Mol in her (2002) ethnography of atherosclerosis, and John Law and Vicky Singleton's (2004) work on the multiple sites and enactments of alcoholic liver disease. As a CLL patient myself, my autopathographic narration is positioned as just one of many narrative dimensions in the network,[8] but an important political element of the research nonetheless, bringing an inside-out perspective to this ethnography of CLL online.[9] In crafting a method that assembles the nuanced mapping of material relations of narrative enactments online, among which sits my own unfolding narrative of living with disease, I hope to create productive intersections between my own narrative enactments of CLL (of which this entire project is one), and a range of other enactments that shape my own. I am to some degree a "native" researcher then (Ellis 2004; Denzin and Lincoln 2008). By inserting my own narrative enactments into the mix, I began this work thinking that I am at once writing from the centre of my experiences and from the margins of a culture in which the diseased, the sick, the dysfunctional are so often spoken *for*. But of course, my experience may be de-centred by others, and I can't talk uncritically of "margins" and "centres" if I accept the flattened ontological landscape of circulating narrative objects, of which I am just one. It is perhaps more fruitful to try to trace the network patterns that keep some actors more strongly tied into positions of control in some enactments of disease than others, and to ask if they might be changing in this new era of digital patienthood. Although an auto-ethnographic presence is very clear in this work, I make every effort to present it as just *one* narrative force in a field of many others I have encountered.

Mol (2002) and Law and Singleton (2004), whose work has been fundamentally influential on my own methodological practices, were located very differently as researchers observing day-to-day physical practices in the field—clinics, laboratories, waiting rooms and so on—and not having declared a diagnosis with the diseases that formed the object of their inquiry. My work, as a CLL patient-researcher, is situated with narrative practices of disease in a virtual field. I am observing the circulation of virtual texts, inscriptions, and stories that signify the material enactments of a disease. That raises an interesting methodological question about the object of study: in a virtual world where all that exists of a disease (or any entity) is textual, do those texts become digital "objects" in their own right rather than merely inscriptions of "real-world" practices? Multiple enactments of disease (or any phenomena) online have to be read at once as separate from the everyday situated practices of doing disease offline and intrinsically related to them. The virtual CLL networks explored here become the digital archives and mediators of inscriptions produced on the ground (research papers, newspaper reports, policy documents) for sure. But they are more than just databases of informational narratives. These narratives are actively mobilized into support networks. They are circulated and shared by key actors. They come into contact with each other and with the online narratives of other human actors in the networks (primarily CLL patients and their carers). They are put into dialogue with narratives *specific* to the online support community—the shared stories of experience that CLL patients exchange in these networks daily. They begin to produce *network effects*. I want to suggest then that when the inscriptions and narratives of institutional disease practice are put into circulation with patient narratives online, a potential for enacting offline practices of disease differently is catalyzed. Where productive narrative network effects are effectively mobilized into the everyday analogue practices they relate to, change might happen. The questions this work needs to ask then are primarily: What are these narratives? How do they circulate? Who does the circulating? What, most importantly, do they tell us about the concerns of those living with and treating CLL and the potential of online narrative circulation to address them?

There is already a vibrant body of work exploring issues of patient empowerment through online communities of illness which are fundamentally concerned with the potential of narrative sharing to effect meaningful change in the way people approach illness. Hoybe et al., for example, identified three different modes of action through which women in online support communities confronted breast cancer:

> *Verbal acts* of writing and communicating experience; *imaginative acts*, embodied in metaphors, re-imagining their experience of the world and regaining power over a life that was shattered by breast cancer; and, finally, *practical action* for withstanding cancer treatment, nursing the body through diets and exercise and educating themselves about their disease. (Hoybe et al. 2005, 217)

The potential for such communities to fulfil a range of needs for cancer patients through varying narrative enactments is clear. In Hoybe et al.'s respondents, the practices of crafting and imagining responses through attention to the communicative act of writing itself sits firmly alongside the practical necessities of communication purely as information exchange. Benjamin's anxieties seem for the moment unfounded. It would appear that the informational does not necessarily exclude the narrative drive. We are, it seems, not easily inclined to expunge the poetic from the database.

Like a good deal of the work in this area, Hoybe et al. take as their object narrative practices in a *specific* online community. This kind of focus contributes much to a fine-grained understanding of very local communities of online narrative practice that may be extrapolated more broadly. In identifying these modes of action, Hoybe et al. aren't concerned methodologically with the narrative flows, intersections and enactments that underpin them—it is not their object of inquiry. Currently, there is very little research to be found on online support communities that wants to take that mapping process on.

There is probably good reason for that. It is a laborious process, and some may say too "flat", too concerned with the metaphysical ontology of narrative objects and network flows to make a difference to the lives of those living with disease.[10] I hope I have already demonstrated why I think it matters that attention is paid also to the *complex networks* emerging from the intersection of a range of narrative forms and themes amongst a variety of actors enacting CLL online.[11] By mapping the narrative distribution of CLL online, I want to reveal what might be learned from a broad, heteroglossic landscape of multiple actors and objects. Part of that may involve exploring the inscriptions that maintain dominant forms of disease definition, and asking if or how "e-patienthood" is enacted to *challenge* the discursive power of those inscriptions. Importantly though, I want to explore how people with CLL *translate*, *accommodate*, *re-iterate* and *re-define* the multiple narrative enactments of CLL online.

In her observations of the unfolding digital narrative written by the father of a boy undergoing treatment for acute lymphocytic leukaemia, Faith McLellan (1997) describes digital health narratives as ongoing, unfinished and unruly texts with the potential to reveal valuable information about experiences of illness not accessible through the more constrained and closed narratives enabled by the print form which are in some sense "finished" and contained by their singular completeness. With their mix of lab reports, journal entry, existential observation, requests for advice, experiential accounts, demonstrations of medical and scientific knowledge, links out to relevant sites and information, and responses to comments from other forum users, digital health narratives are potentially at once heterogeneous and collaboratively heteroglossic accounts. This raises the potential for individual narrative reconstruction online to become an ongoing reflexive project, drawing on and sharing a range of resources that is by its nature collaborative, multidisciplinary, and dialogic.

As well as seeking to fulfil the function of getting presently "hidden" voices out into the public domain, this project is concerned with exploring how those living with CLL and their carers are *themselves* enabled or empowered through online narrative interaction surrounding the disease. Ferguson and his e-patient working party make the preliminary conclusion that "The art of 'empowering' patients is trickier than we thought" (Ferguson 2007, 23), noting that "clinician-provided content has few, if any, positive effects" (ibid., 24) where the patients' own level of engagement with their illness has not undergone significant change.

My aim to map the multiple contextual stories that touch the individual stories of people living with CLL online acknowledges that a disease is always experienced as the combined forces of a *number* of practices and interests. By mapping patient stories and the broader interests that shape them, I suggest we can achieve several things: We can identify the key players and activities involved in holding a particular disease together as a single entity; we can identify the major concerns of those living with the disease; and we can perhaps begin to think about strategies for bringing the different enactments of a disease into more productive alignments.

Diagnosed with a chronic cancer at these crossroads of knowledge and communications technologies then, I am well located to map the new territory as I negotiate it as native and as researcher. Triangulating ethnography, auto-ethnography, with Mol (2002), and Law and Singleton's (2004) ontological interpretation of ANT, this exploration of CLL online asks how multiple narrative objects circulating online translate to the lived realities of this form of leukaemia. Whether patients talk of changed relationships with their doctors, efforts to access trials and drugs, or the understanding of developments in CLL knowledge and treatment behind statements such as "I no longer have the sense that I have a sword of Damocles hanging over my head…" (*In Our Blood* Survey Respondent 25),[12] this work sets out to map those effects.

What can we learn about the various ways in which CLL is "done" to patients, and the way that those patients "do" this chronic blood cancer in an embodied, digitally connected, and increasingly genetically decoded world? What are the implications of digital narrative exchange for an unfolding philosophy and anthropology of illness in a new bio-medical and technological landscape?

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Notes

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[1] Purine analogs fludaribine and cyclophosphamide make up the “chemo” element of the standard CIT regime of FCR, alongside monoclonal antibody rituximab which constitutes the “immuno” element. For around a decade since its inception, FCR has been regarded as the gold standard of care for younger fitter patients, with some patients with particularly favourable biomarkers remaining in remission some twelve years since their involvement in the first trials. However, many patients will in fact relapse within 2-6 years following treatment with FCR, and around 10% go on to develop treatment-induced further malignancies, often superseding CLL with a potentially more deadly prognosis. As CLL specialist Jeff Sharman notes, “FCR is pretty close to the maximum amount of chemotherapy you can put into a single regimen” (Sharman 2012).

[2] According to the Surveillance, Epidemiology and End Results (SEER) Program of the National Cancer Institute, in the U.S., it was estimated that 16,060 men and women (9,490 men and 6,570 women) would be diagnosed with and 4,580 men and women would die of chronic lymphocytic leukaemia in 2012. http://seer.cancer.gov/about/

[3] Two CLL health-related quality of life projects were conducted in 2007 and 2008 recording dramatically lower emotional well-being scores for this patient group in comparison to both the general population, and people with other cancer types (T. Shanafelt et al. 2007; Else et al. 2008).

[4] As Shani Orgad notes in her work on online support communities for women with breast cancer, the potential of online narratives to transform broader public debate surrounding serious illness is to a large extent restricted by the closed/semi-private nature of many online communities.

[5] U.S. physician and writer Tom Ferguson envisioned a medical democracy enabled by the internet in which “e-patients” feature as “individuals who are equipped, enabled, empowered and engaged in their health and health care decisions”. For the fifteen-year duration of his struggle with multiple myeloma ending with his death in 2006, Ferguson promoted healthcare as an equal partnership between e-patients and health professionals and systems that support them (http://e-patients.net/about-e-patientsnet).

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[6] This e-democracy mirrors a wider call for the democratizing of medicine through medical education, including patient involvement (Bleakley, Bligh and Browne 2011).

[7] Faith McLellan (1997) defines the digital health narrative as an "unruly text" in comparison to more traditional literary forms of health writing which, although open to interpretation, are in some sense "finished" and contained by their singular completeness.

[8] Positioning my own narrative as just one object in a network accords with the ontological politics of the project, and as such addresses the critique of visibly incorporated subjective experience in ethnographic work as mere self-absorption, and what Geertz (1988) has disparagingly referred to as "author-saturated texts".

[9] This is designed in line with a reflexive ethnographic approach that "fully acknowledge(s) and utilize(s) subjective experience as an intrinsic part of research" Davies (1999, 5).

[10] For a critique of ANT methodologies see Saldhana's essay, "Actor-Network Theory and Critical Sociology", in which he reviews the following ANT texts: *Complexities: Social Studies of Knowledge Practices*, edited by John Law and Annemarie Mol, Durham, NC: Duke University Press, 2002; *Aircraft Stories: Decentering the Object in Technoscience*, by John Law, Durham, NC: Duke University Press, 2002.

[11] In particular, I am interested in the various interpretations of textual form either as a representational practice within the linguistic field, or as a more Deleuzian interpretation of culture as a material force in which text operates as just one actor in a broader network, and is not regarded as a privileged locus of meaning in its own right: "here the cultural text itself, the narrative, is not to be explored in terms of representation but in terms of how it performs, acts upon us, or materially produces an effect" (Bassett 2007, 23).

[11] In order to accommodate the voices of patients not wishing to have their everyday online narratives used for research purposes, part of the methodology involved an online survey of CLL patients and carers. The survey was launched in January 2013 on online survey site SurveyMonkey, and attracted 360 responses globally which have formed a core part of my findings.

CHAPTER FOUR

FAMILIES AND PHOTOGRAPHY: AN EVERYDAY LENS ON END OF LIFE

LORNA WARREN AND JULIE ELLIS

Introduction

The sequestration of dying from everyday life in modern, western societies is well documented in theoretical and empirical work (Ariès 1976; Elias 1985; Mellor and Shilling 1993; Lawton 1998; 2000). However, social research has yet to explicitly explore photography within contemporary families as a lens through which to interrogate issues of visibility, and to reflect on what such pictures, and the processes of taking them, might tell us about everyday experiences of living with dying. In this chapter, we aim to start a conversation about the role of photographs and image-related practices in the constitution of families who have faced end-of-life circumstances, and the concomitant production and reproduction of social identities throughout the life course.

Situating End-of-Life Photos

In recent years, there have been a number of public exhibitions devoted to exploring human attitudes towards death. In 1995, *The Dead*, a show at Bradford's National Museum of Photography, Film and Television displayed post-mortem images from collections produced by twenty-eight photographers and described by one journalist as "often dismaying and sometimes shocking" (Lubbock 1995). More recently, during winter 2012-2013, the Wellcome Collection in London exhibited *Death: A Self-Portrait* curated by Richard Harris, which included artwork, scientific specimens and items of material culture pertaining to death from around the world.[1] Outside the UK, *Reveries*, an exhibition featuring the work of Australian and New Zealand photographers, opened at the National Portrait Gallery in Canberra in 2007. This powerful collection represented personal experiences of death and dying over the last three decades (see Ennis 2007; 2008; 2011).

There are, in fact, many examples of contemporary professional photographers exploring death and loss in their work.[2] Their images not only capture and document a process; many also represent an attempt to make sense of the loss of someone close, though the focus has tended to be on adult deaths. They transmute personal experience into a public story with images often appearing in exhibitions and publications, on websites and blogs, and in reviews or commentary pieces published in the popular media. Helen Ennis, the curator of *Reveries*, has commented that these artists have played a "crucial role…in bringing intensely personal, often distressing experience into the public domain" (2007, 14). Ennis and the photo historian Audrey Linkman (2011) note that from the 1970s onwards, a shift in western social attitudes towards death made mortality a more "legitimate subject" for photographers to explore in their work. The socio-cultural drivers behind this shift are complex. They include developments from the 1960s onwards in research, death education and the care of dying people; the routinisation of mass media reporting about deaths occurring across the world; and a growing inclination for dying and bereaved people to make public their stories (Small 1998; Linkman 2011). Collectively, these social changes are understood to have contributed to a more general awareness of death within western public consciousness (Linkman 2011),[3] with platitudes pertaining to taboo and modern societies as "death-denying" being subjected to more nuanced analysis (Kellehear 1984; Walter 1991, 1994). Walter's (1994) work on the revival of death, describes a postmodern era within which individuals talk about, and consume, public narratives about death and dying in order to know how to manage these phenomena in their own lives. He argues that with the rise of individualism and secularisation, death has become an increasingly private experience that we negotiate and personalise in the absence of traditional meaning structures and in response to contemporary dying experiences, which characteristically involve degenerative disease and a more prolonged dying process (Walter 2014). Citing Walter's (1994) work and the shifting and uncertain terrain it describes, Linkman argues that it is in this milieu that "photography found a role to bring to the attention of its audience a subject with which many were unfamiliar, uncomfortable and unsure of the appropriate response" (Linkman 2011, 155).

Whilst pictures produced by artists and professional photographers are extremely powerful, these are quite different to the photographic circumstances of "ordinary" families, members of which might also be capturing (or perhaps not) for whatever reasons, their experiences of death and dying in and through photographs.[4] During the nineteenth century, the prevalence of western post-mortem portraiture is well documented (Ruby

1995; Hallam and Hockey 2001; Linkman 2011). As Hallam et al. (1999) explain, it was a practice associated with the family and domestic life where, "[p]hotographic images were used to record the end of life but also to overcome this end in that they provided the dead with a visible presence within domestic spaces" (1999, 35). Images of deceased family members represented an endeavour to construct the identities of kin groups, and as cultural representations, these material artefacts provided a means of allowing the dead to remain socially present (Hallam et al. 1999). Although this practice may have retained its salience in personal mourning rituals, it has become much less visible at a societal level (Hallam and Hockey 2001). By the latter half of the twentieth century as death became a social taboo and increasingly distant from daily life (Gorer 1965), being interested in death and the dead body was considered morbid (Linkman 2011). Consequently, scholars acknowledge that it is difficult to ascertain the extent to which the practice persisted given that if it did take place, it is likely to have done so secretly. There is some evidence to suggest that it did continue as a family practice, but on a rather more modest scale (Linkman 2011). As the photographer Rudolf Schafer commented in 1989, "[p]hotographing the dead is not new…but people do find the idea rather strange" (1989, 194).[5]

As we write in 2014, it is notable that these sentiments were echoed only last year when another photographer, Martin Parr, issued the following challenge to the UK public:

> I am now going to invite you to take a photo at or of a funeral, a tough ask, but who wants an easy assignment? We live in a society where there are unwritten rules about photography, and one of them is that it is perfectly OK—even encouraged—to shoot photos at a wedding but not at a funeral. (Parr 2013)

Parr assigned this task during week two of the *This is Your Photo* project which, in conjunction with *The Guardian*, was part of the *Mass Observation* show at the Photographers' Gallery in London (28 August - 9 October 2013). Each week during the exhibition the project invited members of the public to share photographs of different aspects of their daily lives, which were posted online on Flickr and incorporated into a user-generated, emergent installation on the Gallery Wall. Having viewed some of the images ourselves (and given the short timeframe for the task), we would be surprised if some of the pictures shared, did not predate the announcement of Parr's challenge. In other words, despite the somewhat proscribed nature of photographing death (in British society at least, and for non-artists in particular), we wonder if people already had images in their photo collections that they could share. Reflecting on the research she conducted to curate *Reveries*, Ennis (2011) affirms our speculative hunch.

> I have had the curious experience of being shown extraordinarily intimate photographs of a loved one's last moments on the screens of mobile phones, laptops and desktop computers…It seems probable to me that these technologies are contributing to an increase in the volume of death-related vernacular imagery, including post-mortem portraiture. (2011, 127)

Ennis considers the ubiquitous nature of digital technologies to be critical in terms of innovation in photo-related practice (e.g. digital sharing) and also increasing opportunities for image-taking at the end of life and within family (or non-artistic) contexts (see also Ennis 2007). [6] Despite acknowledging the salience of this, it is something she felt unable to explore and represent in the exhibition.

> My original intention with Reveries had been to bring together different kinds of photography to juxtapose professional and non-professional (that is, vernacular) photographs…I abandoned the idea because the images…were of a different order …vernacular photographs were too specific—and sometimes too emotionally raw—to be presented alongside the highly mediated and self-conscious art works in the exhibition. This, together with their inherent modesty and artlessness, meant that the vernacular photographs begged for consideration on their own terms. (2011, 126)

Crucially, we can relate to Ennis' position. Our work in this area was stimulated, in part, by the highly personal stories of family members and friends. Its importance has subsequently been corroborated by the moving accounts of images in end-of-life contexts shared with us by conference delegates and colleagues who have, moreover, confirmed the importance of looking at deaths across the life course, from birth to later life. As Ennis suggests, these are images that need to be considered "on their own terms", but which have received limited empirical attention. One study (Parrott 2010) exploring the material culture of memory and loss in households in South London, has challenged the suggestion that illness and death are cut out of family narratives and photo albums as too simplistic an account of family practice. Parrott explains that many participants "did not stop taking photographs in anticipation of a person's death", in fact, "the process of anticipatory mourning often prompted them to take more photographs not less" (2010, 131). She goes on to situate her analysis of these images within the context of domestic life and practices—stressing the material and sensory aspects (Edwards 1999) of photos as objects which "do things" to family spaces, relationships and memories.

To understand more about what Ennis describes as "invisible" vernacular photos of death and dying, in the remainder of this chapter we build on Parrott's work to ask what these photographic practices might reveal about how contemporary families are actively produced in the "doing" of daily family life (Morgan 2013, 1996)[7] in circumstances of severe ill-health and when facing death. As the subsequent material generated from in-depth, qualitative interviews with two different families will demonstrate, what we are calling "lay" photographic practices—photos taken by families and individuals without artistic intent or training—can offer a new analytical lens to explore how end-of-life transitions are woven into the fabric of everyday lives. These are *relational* lives[8] that are "embedded (at a material, emotional and metaphorical level)" making it "impossible for relationships to simply end" after death (Smart 2007, 45). Thus, we pay particular attention to the ways in which the images work to construct visual narratives of social identity across life courses (Hockey and James 2005), extending past death and into remembrance (Hallam et al. 1999).

Family Stories

Our starting place for empirical exploration of family photo practices has been an acknowledgement of a gap in knowledge about everyday and mundane aspects of death and dying (Ellis 2010, 2013) and of the power of the visual in capturing alternative narratives about the life course (Murray et al. 2013). As Kellehear (2009) has argued, there remains the need to understand dying experiences outside the dominant discourses of medicine and disease. We therefore asked the individuals from the two chosen families to reflect retrospectively on the images which they had taken as part of their day-to-day lives, over the course of a serious illness/dying process and into bereavement. One participant had lost his wife nearly two years earlier, and the other participants—a mother and daughter—were bereaved of a child and sister respectively almost eleven years ago at the time of the interview. We became aware of the families and their circumstances via our personal networks and we interviewed them in their own homes. The interviews were informal, approached as a conversation with inherent flexibility. To understand photography as a process embedded in relational and material practices of family life (Smart 2007), we asked questions about how photos were subsequently displayed, used and shared, as well as exploring the contexts in which they were taken and why they captured these moments in the first place. With permission, the interviews were audio-recorded, transcribed and analysed using a broadly thematic, narrative approach (Riessman 2008).

David and Pat

David is sixty-three and lives alone. He retired from work early to care for his late wife Pat. They had been together for forty-two years, and married for thirty-six. Pat died from ovarian cancer at the age of sixty-five, subsequent to living with multiple sclerosis after developing the condition in her forties. The couple do not have any children and David describes the relationship they shared as distinctively harmonious, and close. When talking about their life together, David explained he was the one often carrying a camera. He had always taken photos and continued to do this throughout Pat's illness and her decline. In David's words, "*taking the odd picture that's like taking a breath—I didn't think about it*". He was clear that for him, this was about continuity—he did not intend to make a record of Pat's illness and death: "*I didn't set out to do that, I just carried on doing what I'd always done taking the odd snap from time to time*". David alluded to the "everyday" nature of the images he took. About them, he said:

> They were more sort of scrap-booky type snap-shots, bits of … and if it was her birthday, or some flowers or something I took pictures of the flowers —again there was, they were just what everybody does for memory I know some people when they have seen some of the pictures of Pat in hospital being poorly go "Oh no, why did you take those?" Well I did because that's what I wanted to do.

He took photos on trips to the hospital, during stays on the ward, when Pat emerged from the theatre after surgery (Fig. 4-1). He took pictures of her at home after a haircut, and on one occasion with flowers she had received as a gift (Fig. 4-2). David also took photos of their home when Pat was dying there. David explained that the hospital images in particular, became part of a shared viewing practice and a way for the couple to manage the illness experience:

> When Pat was [back at] home I said "Oh this was you sitting or this was you eating your dinner" and she'd say "Oh crikey look at my socks" or something like that. So it was more conversational, it was humour, it was dealing with it.

Whilst the everyday nature and continuity of David's photo practices is important to consider regarding the role image taking is playing in this relational context, David's account does point to a layered set of purposes and meanings behind taking the pictures. Whereas he explains he did not set out to make a record, he instantly reflects:

> I suppose I did realise particularly in the last year when Pat was getting significantly poorly I started to feel that if I don't capture these images I'll think I wish I could remember what that was like. And the image I have got in my head it might be being altered by thought and memories that weren't really there.

Throughout his interview, David revisits this relationship between photos and memory, and his need to retain an accurate sense of what happened during the illness. While this was of great importance to him, he was aware that it was something others struggled to understand. Speaking about a relative, he told us:

> She's very emotional like that and she just couldn't compute in her mind why I'd want to take a picture of Pat not looking very well— [she said] "why do you want to remember Pat that way?" It's not that I don't want to remember her in a happy way but as I said, for me I have to remember Pat in totality, it's the complete spectrum of how Pat was and I recognise that is difficult.

What David describes contravenes the popular adage adopted in circumstances of severe ill-health and when someone is dying, that it is better to remember the person as they were "in life", or when they were well. While this may be the case for many people, the pervasiveness of this view privileges a somewhat static idea of personhood, and one that assumes the onset of serious illness "will disrupt, transform or dissipate a person's identity". (Ellis 2013, 254). That there is a clear "before and after" in terms of who a person was prior to illness and the (non)self they are subsequently, does not fit with the processual understanding of Pat's identity which David seeks to capture in the images—"*Pat in totality*". What David describes here suggests that for some relatives at least, taking images over the dying process is important. However, what his experience also highlights is that these pictures may remain private given societal expectations and the difficulties others may have with viewing the images or even acknowledging their existence. Despite David being relatively open about the photos (he shared photos with close family and friends on Facebook), there are some pictures of Pat close to death which he has chosen not to show to certain relatives.

This raises important questions about the role of display in these circumstances and what happens to images after a person has died. Although David was concerned with creating an internal visibility (i.e. in his own mind), stating, "*it is important to me that I don't forget any aspect of what I knew of Pat*", since her death he has developed a set of *public* practices that memorialise Pat and which through the incorporation of photography blend old and new memories about their relationship. At home, David has what he calls a "*tiny wall of memories*" (Fig. 4-3). Here he displays pictures representing memories from the couple's time together and their individual life courses (e.g. pictures of Pat as a child). David uses this as a relational canvass, continually changing and rotating the pictures.

Fig. 4-1 Pat Immediately After Surgery

Fig. 4-2 Pat Back Home from an Operation

Fig. 4-3 David's "*Tiny Wall of Memories*"

Fig. 4-4 Pat's Ashes on the Hotel Balcony in Hawaii

When Pat was dying, David told her that he would make trips (described as "*odysseys*") to places they had visited together. These journeys are highly significant for David, and he takes portions of Pat's ashes with him to scatter in these various places. The trips also involve taking many photographs (see Fig. 4-4) of which some are shared with friends on Facebook while others are placed on the memory wall.

> When I've been on my odysseys the small circle of friends that I've got on Facebook I know virtually real time they'll get a little ping on their machine and they'll go [to] me sitting on a balcony with Pat's ashes on the top explaining how she was drug-tested on the way to Maui or pictures of me on top of [mountain], I go back to the hotel sort of key it in and log in and within minutes I've got clicks with my friends' likes or comments.

Pat is made present despite her bodily absence within these odyssey pictures. For David they are about "*creating new memories for yourself*" which he then shares with others via social media. Walter (1996) has identified how bereaved individuals need to talk about their loved ones to create an enduring biography and place for them within their ongoing life. David's sharing practices around photography seem to speak to this co-dependence between bereavement and biography. In another poignant example of sharing, David refers to talk which goes beyond an established group of family and friends. He described an emotional encounter with a sales assistant during one particular trip. She was moved by his story and after returning home David sent this person a copy of a photo he had taken during his holiday. He explained:

> And that's a new memory created from the older ones—I get emotional about that because I hadn't met the woman before. Within a few minutes of our conversation—and she was a sales person and I was buying—oddly in a, in an emotional sense (pause) we made a connection through Pat…It made a shopping experience completely memorable.

Crucially for David, photos are identified as key material manifestations of memory, and for him they allow a *continuing* narration of his relationship with Pat which interlaces memories created both before and after her death.

Jennifer, Nina and Lucy

Jennifer is fifty-four years old, and with her husband Robert, they have four daughters. Their eldest daughter, Nina, is fourteen, their second daughter Lucy would have been eleven, and they have seven-year-old twins. After their second daughter Lucy was born, she was transferred to a special care baby unit where she died when she was three days old. In her short life, she experienced a number of medical procedures and required a ventilator to help with her breathing. She was cared for in an incubator which made it difficult for her parents to cuddle Lucy and be physically close to her.

On the morning she died, the medical team explained that Lucy's condition had deteriorated. The couple and their eldest daughter Nina (aged three years) came together at the unit to be with her. A consultant who had been caring for Lucy throughout the night offered her personal digital camera to staff, so they could take pictures of the family together. The photos that were taken show Jennifer, Robert and Nina with Lucy during her dying moments, gathered around the incubator. After she had died, the family were supported to take their own pictures and the camera was handed to them to use while they spent time with Lucy in a family room which had sofas, a baby bath and a crib in the corner (see Fig. 4-5). Some members of the couple's immediate family, including Robert's parents and Jennifer's sister, came to the unit, and pictures were taken of them nursing and holding Lucy. A short while later, the consultant put the images onto a CD and returned it for the family. Jennifer and Robert had prints made from the digital files, and these photos are now stored with other collections of pictures. These include pictures of Lucy at their home, when they had the chance to take her body there for a couple of nights, and photos from her funeral which took place nearly four weeks later.

Fig. 4-5 Nina Holding Lucy in the Family Room

When Julie arrived to interview Jennifer and Nina together, she found that a number of these photographs are now displayed prominently around the family home and in most of its rooms. As Jennifer explained:

> I wanted her (Lucy) to be present in our dwelling and with Robert's input we chose the pictures out of some of the ones that you (Julie) have seen …around our house, had them enlarged, framed them and…placed them around the house. It was really important to us to do that…they've been here ever since.

It is clear that the family use these photographs as a way to ensure Lucy has a presence within the everyday spaces of their continuing family life. The importance of embedding a memory of Lucy within the physicality of their home resonates with their behaviour at the time they brought her body to the house, and is reflected in the moments of this time that they chose to capture in photographs. The images show it was significant for Jennifer, Robert *and* Nina, to have some "normal" family time with Lucy and for her to "see", and be present in, the routine spaces of their home. As Nina explained when discussing one of her favourite photographs:

> Yeah when we came home (after she had died) I think I was just so glad to finally have Lucy and be able to sort of interact with her more as I said, I took her all around the house narrating each room and then when we got back here I think I read her story books and there's a picture of me with a red teddy bear…and I'm sort of playing with her like with a teddy bear in front of her face and things and I brushed her hair.

As Nina's playful ease indicates, doing "normal" family things (despite the far from "normal" circumstances), and having Lucy home was a comfort to the family. This was the case for Jennifer in particular. She spoke about the day that Lucy was to be returned to the hospital following her short stay and how difficult that was. It was on this morning that she and Robert took pictures of each other nursing Lucy in the bedroom that would have been hers. Another photo was taken of a neighbour who called at some point during those few days. She held Lucy in her arms and Jennifer was very touched by this. It is after all, the kind of picture one might expect to see amongst an "ordinary" collection of baby photos which often capture the procession of visitors punctuating a baby's first few days at home. Jennifer and Robert made copies of some pictures for family and friends—again, a common practice for parents with a newborn child. In fact, it was during the interview when Jennifer rediscovered a note amongst the photos in "*Lucy's box*" that she had penned at the time to remind herself who should receive copies of which photographs. As a scrap of paper, it was a very mundane find, but at the same time, it was immensely poignant. What the images from the family's home collection in particular highlight, is the role of "normalcy" or "mundanity" that is inherently present in even the most emotionally raw experiences—something it seems the family were keen to capture and preserve in photos.

For Jennifer and Robert's children, the photos play an important role in connecting Lucy to the family's biography and making her a "real" person (Layne 2000). This is especially the case for the twins who were born after Lucy's death. Jennifer explains how the photos help the twins to know the sister they never met:

> This clearly predates their existence but Lucy was really real, they can really see us—you (Nina) —in those pictures, they know and can see people that they are familiar with now and she is there with us. And to me that gives, that whole part of that experience a tangibility that might otherwise be hard to convey with just words and recollections.

Jennifer has not shown all the pictures to the twins, but she hopes that in the future they will want to know more about their sister and then the photos will be used to narrate and structure conversations about what happened in Lucy's short life. For Nina, it is a little different, as she can remember spending time with Lucy. However, the legacy of the images and their narrative power means that the photos are completely intermeshed with her memory of Lucy's life and death. She told us:

> Yeah, I think as I've got older I've sort of become more frustrated about how I want to remember her but I don't want to remember a photo, I want to remember something that actually happened, that I actually remember not, I'm not remembering a photo that has just been put into motion.

There were points in the interview where Jennifer and Nina checked with each other what Nina could remember. Significantly, they *both* drew on the photos, with Jennifer also using details in the pictures to try to sequence events and inform her memory. It was especially striking to see how Nina grew from an unsure child in the initial images taken by the incubator when Lucy was dying, into a protective and proud big sister in subsequent pictures. Still by still they show this relationship as it is "told" through bodily proximity, touch and facial expressions captured by the camera. Discussing Nina's behaviour at Lucy's funeral the following exchange between Jennifer and Nina reveals this:

> Jennifer: But some of these are absolutely gorgeous pictures, I really treasure them. Again it was another opportunity for Nina to be proud, to be photographed, to enact being a big sister really. I just love that one, you look so sweet.
> Nina: I like that one cos it looks like I'm a proper big sister. It's that one.
> Jennifer: Oh this one yeah.
> Nina: It's that one, it's like I'm pushing mum away—like I want to hold her myself (pause). (See Fig. 4-6)

In dialogue throughout the interview, what Jennifer and Nina share demonstrates how the photos help to produce their sense of family, and in particular, an enduring sibling relationship for Nina and Lucy. As we see here, it is through their conversations and looking together, that a role as big sister to Lucy is constructed for Nina and is afforded an experiential depth. This is despite the brevity of their time together and the vagaries of Nina's memories. In talking about what they see in these photos, mother and daughter co-construct Nina as a sister to Lucy, whilst at the same time keeping Lucy relationally embedded in ongoing family life. This enduring sense of a big sister relationship is very much enacted by Nina today in her day-to-day life, as she proudly insists that she *has* three sisters and she plays an active role in anniversary and memorial celebrations for Lucy which the family organise and take photographs of each year (e.g., baking an age-appropriate cake for Lucy's birthdays, putting decorations with pictures of Lucy on them onto the Christmas tree, laying flowers and posting tributes to her sister on her Facebook page).

Fig. 4-6 Nina with Lucy at Lucy's Funeral

It is not only Nina who experiences immense pride in remembering Lucy. Both mother and daughter are very much united in their determination to assert her presence in ongoing family life, despite the fact that some members of the family have not always found this easy to negotiate within the confines of their own personal grief. That Lucy should have a personhood that extends beyond tragedy is very important to Jennifer and she uses the photos of Lucy to ensure she actually has visibility as a member of the family. One particular story Jennifer told illustrates this very poignantly. Since shortly after Lucy's death, Jennifer has worn a silver locket with a tiny photo of Lucy inside and a lock of her hair next to the picture. For Jennifer the locket, which she described as "*the medium of the hidden photo*" (especially meaningful in this context), has acted as a broker of conversation as curious children in particular, (including the twins) ask to see inside. Over the years, these moments of curiosity have precipitated opportunities to talk about Lucy, and to bring her into the flow of daily life. However, as the following extract from their interview shows, this locket had further more "strategic" uses that are directly linked to the practice of family photography itself.

> Jennifer: There've been occasions when after [the twins] were born and their cousins when my father-in-law has said he wants to have a picture [of] all the children and this always used to tug at my heart-strings cos I thought well it, it really…
> Nina: It's not all the children.
> Jennifer: …Isn't all the children—yes exactly—it isn't all the children, is it? But sometimes what I do…
> Nina: That's why we sort [of] have school photos with Lucy in them cos then it's like mum saying it is all the children, it's not just me and the twins, it's me and the twins and Lucy—it's all the children.
> Jennifer: I don't do this so much now but when they were all quite young if I was in the photo I would just quietly open my locket on my neck so some of those photos…
> Nina: I never knew that.
> Jennifer: Lucy is in them. I don't think they noticed but that was really important to me to do that, to say well actually she does have a place in the family.

The school photos referred to by Nina are also a way that the family have strived to give Lucy a sense of biography. Although she has not physically aged alongside her sisters, the inclusion of a photo of Lucy within these particular occasion images, reminds them, and those who receive a copy (as often happens within families) that Lucy is part of their family and the life course transitions her sisters experience. So, as Gibson (2004, 98-99) did when taking a picture of her dying father whilst holding a scan of her unborn baby, over the years the sisters have assembled for their annual school photo, with one of them holding a picture of Lucy within the image. Crucially, Jennifer feels the photos and the practices that the family have developed around them are about trajectory—creating a sense of Lucy moving through life and its various life course transitions with them.

> I suppose what I've done, a lot of the business with the pictures is sort of compensatory in that way and [I] wanted Lucy to have made a mark…You imagine you are going to have those experiences and they didn't happen so a lot of what I did was perhaps compensatory to try and get as close as we could to that life we'd imagined, that trajectory that we imagined we were going to go off on…What I really do feel is that Lucy is really part of that trajectory you know we've managed to weave her in and it's not as good as having her here and the photos will never move or surprise us or do any

> other things we would like them to do but she is a presence, she is a member.

A Lens on Everyday Dying

The family experiences analysed in this chapter highlight that photos in end-of-life contexts are inextricably bound up with matters pertaining to memory and its intersection with everyday practice, personhood and visibility. In particular, we have discussed how these accounts suggest a more complicated view of identity and of “family” as an ongoing process (Hareven 2000). David’s experience asks us to reconfigure the popular idea that people want to remember (should only remember?) a person as they were “in life” or when they were truly “themselves” before their illness and the depredation of decline. With his story, we are asked to consider a more processual and fluid conceptualisation of identity and to wonder how many other families have photos in their albums that speak to this idea of a “totality”; or in other words, a sense of capturing transitions across the entirety of the life course. For Lucy, it is perhaps more accepted that her family would have/want pictures of the end of her life as for small babies their “in life” selves are blurred inseparably, perhaps, with their demise and death. For Lucy’s parents and siblings the photos they have of her are not only about remembering a part of her totality (as David explained about his pictures of Pat), they are intermeshed inextricably with her totality, with who she *was* but also who she *is* and continues to be. We see in their innovative and enduring practices of memorialisation which incorporate the images and involve the taking of new photos, there is a continual dialogue between relational past and present.

To be sure, the tale of popular photography is also a story about the (re)production of “family” (Sontag 1977; Bourdieu 1990). When cameras first entered the sphere of domestic life with the introduction of the Kodak in 1888 photography became, “…the family’s primary instrument of self-knowledge and representation—the means by which family memory would be continued and perpetuated, by which the family’s story would henceforth be told” (Hirsch 2012, 6-7). In this chapter, we have seen this is also the case in end-of-life circumstances. Photographs and the practices they shape help individuals to constitute themselves as family during the dying period, into bereavement and throughout continuing trajectories of relational life. Through family stories, we have endeavoured to demonstrate that often the content of lay images *and* the practices that surround them, in spite of the extraordinary circumstances within which they are taken, embody and reflect traces of the everydayness of relationships and family life. We argue that they offer insight, and a way to talk about the everyday experiences of dying and bereavement.

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Notes

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[1] For more information go to: http://www.wellcomecollection.org/death

[2] For examples see: Briony Campbell, *The Dad Project*; Angelo Merendino, *My Wife’s Fight with Breast Cancer*; Pedro Meyer, *I Photograph to Remember*; Nancy Borowick, *Cancer Family, Ongoing*.

[3] However, at a personal level in terms of preparing for one’s own death or the death of a loved one, a recent 2014 study commissioned by Dying Matters (National Council for Palliative Care) found that a majority of the UK public do not consider their wishes and make plans for death (see: http://dyingmatters.org/news/millions-leaving-it-too-late-discuss-dying-wishes).

[4] We recognise that this is not a case of binary either/or categories. In many circumstances where professional photographers are undertaking projects about the end of life, they have what Briony Campbell (2011) has called a “dual role”. She identified her own as that of daughter and photographer and has reflected since her father’s death on whether it is “actually possible to be a daughter and a photographer at once” (2011, 5).

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[5] However, as Linkman (2011) notes, by the end of the twentieth century a particular type of post-mortem photography experienced a "rebirth" (2011, 80). In the case of stillbirth and the death of a very young baby, there are now professional guidelines which neonatal and special baby care units follow to support parents with their loss, which includes taking images of the child for memorialisation purposes (see Hochberg (2011), Osborn, (2000) and also Hughes et al. (2002) for an alternative perspective and evidence of possible adverse effects).

[6] See Burch (2009) where a medical professional discusses relatives using mobile phone cameras to take pictures of loved ones after they have died in hospital.

[7] Morgan's (1996) seminal work on family practices argues that family is actively produced by individuals "doing" things together in day-to-day life (e.g. eating practices, caring practices). It acknowledges the fluid and flexible nature of "being" a family.

[8] Building on Morgan's (1996) work on family practices, Smart (2007) argues that contemporary lives remain (in opposition to theories of individualisation) deeply embedded in relationships and with a sense of connection to others (they are relational).

CHAPTER FIVE

PATIENT IDENTITY: A VISUAL AND CRITICAL RESPONSE

ANNASTASIA MAKSYMLUK

I am interested in the experience of being a "patient" and the ways in which "patienthood" affects one's sense of identity and "self". As this is a subject that remains relatively under-explored and under-theorized, this paper explores the experience and parameters of "patient identity" by using autobiographical texts and imagery created during my own experience of hospitalisation. "Patients" are defined as those persons receiving medical treatment. Thornton (2000) clarifies and extends our thinking around the term "patient" to acknowledge the ways in which understandings of the term derive from "adjectival definitions: sustaining pain, &c, without repining; not easily provoked, long-suffering; waiting with calmness; persevering". Here the phrase "without repine" is used to indicate an absence of fretfulness, discontentment or audible response. Thus, Thornton's construction of "patients" represents "stoical passivity".

Such constructions of patient identity can be seen to reflect positivist nineteenth-century developments whereby the sciences were separated from the humanities and the foundations of scientific medicine were laid. By means of this division, "the concept of disease became objective" (Engelhardt 2000, 354). This emphasis upon disease and the detached observation of signs and symptoms served to position "patients" as passive objects rather than embodied subjects, as suggested by Foucault's (1975) model of the panopticon and modern disciplinary power, wherein observation is utilized as a form of control, thereby affecting individual behavioural change. Foucault's writing also illuminates the ways in which we are all subject to practices of surveillance and indeed, as researchers, we often perpetuate these practices when we extend the gaze upon our research participants. However, identity ruptures can have a negative impact upon a patient's sense of well-being. This may continue after leaving hospital and highlights the problematic or negative memories which arise from the experience of patienthood.

For the purpose of this research paper, I have chosen to turn the gaze inwards upon myself, rather than observing an "Other". As such, I have chosen to examine my own subjectivities, fully aware that the strategies for turning the gaze inward may also involve an internalization of the practices of surveillance and governance. My emphasis was upon artistic formats, most especially the process and production of autobiographical writing, a form of "evocative" and analytical autoethnography (Ngunjiri et al. 2010) and imagery—and these formats also informed my method of analysis.

Fig. 5-1 Patient Identity

After leaving hospital, I assumed my familiar social worker and "academic" identities. With this in mind, I re-visited the textual and visual material I had produced. I discovered that the imagery and autobiographical writings contained gestures towards key themes I had experienced whilst assuming the identity of patient. I decided to return to my identity of patient with the aim to represent what and how I experienced within those particular forms of subjectivity. I also wanted to draw upon my "insider" positioning (Narayan 1998) and include an additional layer of triangulation and validity by sharing my imagery with a service user called Andy. His responses provoked and furthered my initial understandings, highlighting the ways in which "patient identity" is co-produced and extends beyond the time actually spent as a “patient”. My research also suggests that all players within healthcare settings ought to pay attention to the potential influence upon patient identity, pre- and post-hospitalization. Furthermore, this chapter suggests that arts-based methods may be used to assist in maintaining the “patient” within the centre of the frame.

Key Aims of the Project

As a social worker, I was interested in the ways in which a patient’s experience of “identity rupture”, “repair” and “de/re-stabilisation” might be more fully understood and shared with health practitioners and social care workers. I decided to collate data (images and written responses) via my “insider” positioning as a patient, rather than as a detached researcher observing participants within a research study. One important aim of the project was to demonstrate the potential of the arts to explore subjectivity and chart movement away from limited conceptualisations and understandings of the “passive” objectified patient. Triangulation and validity by someone who had experienced “patienthood” many times (Andy) was used as a form of witness and testament. Andy’s response was important as he had been subjected to loss of autonomy via section under the Mental Health Act, 1983.

Methodology

Autoethnography extends the gaze beyond the individual towards the context. As such, context and subject are interwoven; the researcher unravels the points of inter-connection and tries to establish whose interests are being served within any given situation. I therefore utilized autoethnography as a research method in this project as it is qualitative, self-focused, and context-conscious (Ngunjiri 2010). In addition, I utilized arts-based methods of photographic image making (by using the camera within my mobile phone) and created written narratives in order to make explicit theorisations about “patient identity” and the consequential production of “sets of social relationships”. One of these images highlighted the importance of privacy for patients within a hospital setting and their ability/inability to invoke privacy. This prompted me to question whether caregivers in clinical settings are able to allocate time in order to consider the seemingly “minor” needs of patients and their potential ability to respond to threatening and/or oppressive regimes.

My Experiences as a "Patient"

My writings and images invoke the practices I witnessed and experienced. These emerged as follows:

Occupying a Liminal Position: Being at, or on Both Sides of, a Boundary or Threshold

Whilst waiting to be seen by a doctor at an Urgent Care Centre, I occupied neither the position of healthy person nor assumed the identity of "patient". Occupying a liminal position of being at, or on both sides of, a boundary or threshold can result in accompanying anxieties which affect well-being. I was left alone to bear my pain for four hours. At points the pain was so excruciating, my only relief was to rock back and forth in my chair and cry. This was highly stressful as these acts ruptured my projected public identity as a morally and culturally competent actor.

Usually, our sense of self not only involves who or what we believe ourselves to be but also directs how we choose to respond to social experiences and how we hope to be regarded by others. With this in mind, we act in order for the reflected image to match the information we hold about ourselves. However, my pain reached a point where I lacked the ability to exert the desired level of congruence. As my new identity as "patient" had not yet been attributed, I occupied a position of liminality and experienced a perceived loss of status, severed from my previous identity as a competent social actor. Because I was left unattended, I was not publically "marked" as a "patient". Medical attention or the wearing of symbolic "patient" clothing would have served to indicate my new identity, but I was left to negotiate my ruptured identity without signifiers.

Acts of Ownership

I knew I had crossed a significant boundary when I moved through gate-keeping practices conducted via acts of "ownership". I was assessed as unwell enough to warrant hospital attention and my care and well-being was passed over to the public "ownership" of the hospital. Two physical objects—the hospital wristband placed on my arm and the allocated bed—visually marked my formal admittance into hospital and confirmed the new identity as hospital patient.

However, my induction as a new "patient" was not defined by an accompanying sense of "welcome" or humanity. To illustrate; I was hastily taken by wheelchair to a poorly lit, four-bed ward and left alone on "my" bed. I felt vulnerable, tired and in pain. I yearned to revert to my child identity, to cry and be comforted. For a seemingly interminable length of time, I was—once again—left unattended. This was unexpected. Sitting on my hospital bed, wearing my wristband, I had positioned myself as a patient to be "attended to". When this did not happen, my anxieties increased. Eventually after about fifteen minutes, when a nurse came to the ward in order to check another patient, I was "noticed", brusquely acknowledged and attended to. I perceived myself to be an unwanted addition to her quota of responsibilities. As she collated paperwork and attended to administrative duties, the dominant relationship appeared to be one of responding to bureaucracy, rather than my needs. Within these actions, my psychological losses were not addressed.

As a patient, I was prepared to relinquish certain freedoms as part of entering into a benign paternalistic relationship; I envisaged placing my best interests into the hands of a wider social structure, the hospital and all who work there, and the wider medical profession. The hospital is part of a universal National Health Service and so my acquisition of "patient" identity was an explicit gesture of public "ownership" whereby I chose to accept a limited degree of agency in order to achieve restoration of well-being.

Loss of Status as a Competent Subject with Knowledge of My Own Body

Continuing losses ensued. As Foucault argued in *The Birth of The Clinic* (1973), the patient becomes a signifier of illness and thus experiences loss of status as an individual. The professional act of looking for disease via the medical gaze renders the patient partially invisible whilst the body is viewed for signs under the "medical gaze", *without* the corroboration of the interrogated subject (Eccleston et al. 1997, 700). In accordance with this, whilst I was in hospital I witnessed tensions escalating around me and seemed to relinquish my authority and my knowledge over my own body, even though the practices around me directly affected my well-being. Hospital procedures meant that nursing staff had very little time to carry out their work—and appeared to read only the most recent entries on my records. Unfortunately, this practice led to maladministration of pain relief and anti-coagulants. In order to counter this, I attempted to engage in a dialogue about my care with nursing staff. When a visibly stressed and time-challenged nurse closed this process down and thus silenced me, my passive patient identity was reinforced. I was therefore defined as passive although I needed to be active in order to ensure that similar errors did not re-occur.

I also witnessed nursing staff being subjected to processes of information collation. Acts of nursing appeared to be subjugated to highly proceduralised, mechanical, digitally monitored processes. These were actualized via a system of monitoring of each patient at set points. Each patient was asked the same set of questions. In terms of the playing out of relationships, care of patients appeared to be subsumed to information gathering. If we view "acts of care" through the lens of ritual information collation, the time to care for a patient seemed prone to reduction. Furthermore, a patient with additional needs—i.e. those which lay outside the parameters of the checklist or which rendered the information more complex—were perceived as not acting in accordance with managerially ascribed patient identity.

Privacy

Visual markers stating "Please Ask Before Entry" were placed on the curtains around my hospital bed. However, these signs appeared to become invisible to staff as they were neither acknowledged nor acted upon. Amidst an unthinking ritualistic adherence to proceduralised ways of working, my curtains were routinely removed and I was exposed as a patient. I noted that hospital staff seemed to possess a naturalised belief that patients were required to be available to public gaze. Thus, relationships of power were enacted to maintain the priority of the medical gaze and re-definitions of privacy within a hospital setting. These acts served to reinforce my passive positioning, my lack of control over the position of "my" curtains and my failed attempts to establish a sense of privacy, solace and quietude amongst the chaos and fear.

However, at times, medical staff did confer privacy upon me. This took the form of staff covering my breasts and/or genital areas prior to any physical examination. I protested that the connection between maintenance of dignity and the material covering of the breasts or genitals was of little consequence to me, whereas being able to assert my own boundaries in relation to privacy was of high importance. This further compounded my sense of loss—as I was deemed unable to make decisions about the privacy of my body nor to desire an extension of personal boundaries beyond a small area around my breasts and genitals.

Moments Which Made a Difference: Exerting Agency—Taking Ownership—Creating my Own Image

Within the hospital setting, my abilities to perform my identities were constrained. Outside the hospital, I occupied multiple identities including that of female, introvert, academic, mother, lover and friend. In hospital, I was too unwell to exert my preferred levels of control over my gendered female or introvert identity. I wore the standard hospital gown to counteract the constant sweating I experienced in response to my infection. However, this served to further infantilise me.

Burke (2000) argues that individuals construct self-defining "in-situation" meanings via which they store their own identity "standards". During my time in hospital, I experienced discrepancies between my constructed and perceived identities. My inability to protest against the behaviour around me or to exert forms of agency added to my mental, bodily and psychological stresses, and conflicted with the sole focus upon "bodily" observation by the medical personnel. Burke suggests that in order to alleviate tensions arising from threats to and dissonance with identity standards, individuals draw upon various intra-psychic strategies. Nach et al. (2010) suggest that these may take the form of behavioural techniques (e.g. confronting the identity-threatening event) or cognitive strategies (e.g. reassessing our core beliefs). Alternatively, we may choose to draw upon emotion-focused strategies, to reduce the negative emotional impact and increase our sense of well-being.

Emotional strategies do not necessarily alter a stressful event but can act to re-frame unproductive, negative experiences and perceptions. In my case, I employed emotional strategies as a means of integrating my patient identity (as a self-defining memory) with my already held identity standards. As a "patient", I did not have access to a Dictaphone, was unable to write as I was on intravenous medication, and could not use a mobile phone as they were prohibited within the clinical areas I inhabited. However, when I was able to leave the ward, I visited the day room, used my Smartphone to produce a set of images and produced an autoethnographic account of being a patient. These acts served to enhance my perception of who I was/am and restore my sense of academic-identity. Rather than being the object of the gaze (of others) and/or a "docile body", I was able to make choices about how to illuminate the relationships I had experienced as a patient, reflect upon my "self" and my wider context, and exert agency.

Andy's Voice

This paper contains an explicit over-layer—the voice of Andy—my friend and service user. Andy has been attributed a patient-identity for over twenty years and has been subject to compulsory admission to hospital under the Mental Health Act 1983. Andy regularly interacts with social workers, community psychiatric nurses and consultant psychiatrists as attempts are made to regulate his medications in order to enhance his (social) functional abilities. However, Andy's interactions with professionals appear to be predicated upon the effectiveness of biomedicine, rather than "the shared meaning of illness" (Jones 1999, 7).

Andy and I were both able to use imagery in order to assuage the impact of illness-related identity disruption and stimulate our thinking about how we represent ourselves. Images acted as triggers for us to stand back and investigate self-defining memories of patient subjectivity. These memories were not produced in isolation but were triggered by certain sets of relationships. Andy made visible, complex responses to the attribution of patient-identity, thereby articulating his implicit awareness (Edgar 2004) and repositioning himself as a cultural producer, participating in processes of meaning making (Hanrahan 2013). Together we shared contextual meanings and understandings, thus providing multiple voices as part of an evocative, politicized text.

Andy's Responses

> A man is in the doorway. A doorway is a transition from one room to another.
> Does its presence act to suggest one dimension to another?
> Is he coming in the door or going out backwards?
> Is he accidentally invading upon a personal moment?
> Which boundaries is he disrupting—what is defined as public space & what is private?
>
> The subject is facing the window.
> Is she trapped? She can see outside (where wants to be?)
> She is not exiting via the door—is she unable to move on/can't get well?
> Is she powerless to get well and emasculated?
>
> Gender. The man is in uniform. The woman is in a nightdress—not public attire—
> yet, she is in a public space—is she feeling vulnerable?
> He is positioned in the doorway. Is he opening the door to let her out?

Or closing the door to restrain her/not help her as she would want?

She has not turned around.
If she has seen him, she is not acknowledging him.
Is this an act of resistance?
She appears alone even though there is another presence.
Isolation? Alienation?
Reinforcing mortality and experiencing ill health/dying in a solitary state.
We move onto another state alone, even if we have professional and/or personal, workers/supporters.
She appears ethereal/translucent—Is this gesturing that we are more than the physical body?

Analysis

What is identity and why are considerations of identity important?

This project was motivated by the understanding that concepts of identity are linked to the question "who am I?" We can categorise identity in an individualized manner; connecting it to personality or individual traits which partially serve to define someone in an adjectival manner—for example, as "kind", "hard-working", "extrovert" and so on. However, identity is more complex than concepts of personality. This project highlights the importance of relationships in identity-formation, and seeks to critique concepts of "passive" patient-identity.

Identity as Relational

Examinations of identity and identity-formation prompt us to consider the "relational" aspects of identity and our active engagement with others as we choose to identify with a particular identity or group(s). Thus, ideas of "detachment" need to be adjusted in order to acknowledge the effects of influence, culpability and vulnerability upon identity-construction. Our ability to choose to share particular identities with others is variable. Wider social structures may present influential forces beyond our control. But identities are also multiple—as we demonstrate aspects of personality, role affiliation and membership within groups—and fluid/dynamic—as we indicate who we are for others to see, as well as ourselves. Therefore, identity reveals our similarities and differences to "others". These similarities and differences are mediated by symbols and representations and communicate information, desires and needs. Furthermore, we exert agency, which is the degree of control we hold over the actions which construct and validate our identities.

Explorations of identity reveal the tensions that an individual may experience or may have to negotiate in order to achieve and maintain his/her "desired" identity. This also reveals the level of control or constraint we may experience from others. If we think about power, we can consider power as commoditized in terms of power relationships between individuals or as fluid, dynamic and gaining visibility within relationships. Foucault (1975) suggested relationships of power need to be considered and analysed as they become apparent within the moment, at a micro level. Therefore, when we explore how agency is manifest or restricted, in order to perform an identity, we are examining the playing-out of relationships of power.

The starting point for this project was the material reality of an unwell body in terms of individual experience. However, the unwell body is defined by interpretations within sets of relationships, such as between health professionals, friends and family, and the physical environment of the hospital. Concrete practices are exerted between health professionals and the unwell body. These practices chart out and map the patient identity. As soon as we enter into relationships, our capabilities of "knowing" become minimized due to the inherent complexities that interaction with the Other presents whereby we are limited to the realm of tentative interpretation. We may seek to assuage the discomfort of "not-knowing" by seeking answers. However, this analysis aims to extend understanding by asking questions.

Data as Triggers for Questions

The beginning of a process of patienthood begins a process of questioning my place and space in the scheme of things. Perhaps such a response indicates how distance and perspective become foreshortened and distorted within the hospital setting and so the patient may experience anxieties as he/she endeavours to ameliorate any resultant discomfort and make new meanings. A further process of questioning lies within the blurring of boundaries. As indicated within the data, I was unable to define my external boundaries via acts related to privacy and the marking out of territorial space, but furthermore, my initial and final images draw upon the use of reflection as a visual tool. Within these particular images, I chose to define myself via a representation of a reflected self. This encourages further questioning which challenges positivist ways of "knowing" only that which appears as present and thus "knowable". But, is the “patient” only the material exterior body that can be surveilled? What has physical substance and what does not?

My data suggests a subject simultaneously existing in various realities—the inner world of the hospital room and the outer, wider environment as suggested by the reflected selves. Within the data, the reflected self is perhaps more indicative of the fullness of personhood and thus of the various identities inhabitable—possibly because the reflected self exists on the boundaries of the public space that is the hospital but also in the extended public space of the wider environment.

This consolidates the dominating aspect of “patient” identity from the data, that which is marked out by losses and deficit.

Possible interrogations of the data may therefore pertain to the loss of personal sense of self and loss of public self. This may also be accompanied by the loss of previous identities, such as those of wife/mother/worker. The resultant identity available to me, that of “patient”, carried less status in terms of my meaning making, if only because it carried connotations of passivity and lack of choice, all of which were borne out within the data.

Within my final image and contained within Andy’s responses are a series of questions prompted by the symbol/marker of the hospital wristband. This object conveyed much in terms of identity as relational. When worn by the bearer, it is visible and as such, serves to reinforce the losses of public identities. The wristband also holds particular significance for a viewer as a visual marker which serves to objectify. However, our responses enabled a process of mapping out the humanity denied by the objectified patient, thereby resisting such de-humanisation by being alert to limiting practices and their corresponding symbolism.

Finally, any analysis must consider the motivations for the research itself. Andy questioned whether I might have taken the photographs in order to substantiate my sense of self. Furthermore, he asked whether I had used the camera as part of an act of restoration. It is interesting that such questions were asked of a woman who undertook this process whilst inhabiting a place of healing, rather than within a context of conflict and/or deprivation.

Discussion

I am prompted to ask whether caregivers in clinical settings might be allowed time in order to consider how seemingly minor acts (such as lack of privacy) might be interpreted by patients as threatening or oppressive. In the *Sociology of Health and Medicine*, Topo and Iltanen-Tähkävuori

(2010) suggest that more attention is paid to the psychosocial environment than to the physical environment. However, within the care environment, psychosocial and physical elements ought to be aligned towards enabling patients to exercise agency and maintain/reframe identities of their choice.

Secondly, as part of the health and social care profession, I question whether more attention needs to paid to the ways in which patients process their experiences of biological and identity disruption, prior to, and after leaving hospital. Can we work alongside service users to listen to their experiences of patienthood, and where necessary, assist to re-frame unproductive self-defining memories as part of a process of embodied integration?

Thirdly, do arts-based methods have a role to assist with this process? I am interested in the possibilities of using a device to trigger information and generate creative practices—such as images and writing—that project and interpret experiences. Andy's writing, for example, reveals that his experience of patient identity was linked to his gendered reading of a woman's experience in hospital. The image allowed both Andy and I a sense of safety and control, whilst also enabling a process of distancing. As Walton (2012, 725) suggests, visual-sensory approaches often facilitate critical distance in recognising and considering sensory information:

> There may be an assumption that the aim of arts work is emotional expression at the expense of analytic understanding.

My autobiographical writings draw upon Burke's theorisations about coping response and Nach and Lejeune's (2010) concepts of the cognitive and the emotional. My research gestures towards the difficulties of working in a holistic manner within frameworks of "objectification" and "separation" to the detriment of multi-layered ways of working and processing. This was exemplified by Andy's interactions with health professionals which predicated upon the effectiveness of biomedicine rather than "the shared meaning of illness" (Jones 1999, 7; Hanrahan 2013). I believe this exploration demonstrates the necessity of working alongside individuals in order to see how identities are mediated and co-constructed and the ways in which self-defining memories are embedded. Application of visual and sensory devices allows workers and service-users to share and validate different types of "knowledge", thus extending the textual towards more productive, intuitive, experiential, unconscious and emotional ways of knowing. Working in this manner may act as a conduit towards cognitive rational and linguistic processing—or may serve as an end in itself.

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PART II

ILLNESS, MEMORY AND REPRESENTATION

CHAPTER SIX

THE PIN-UP AND THE CORPSE: EROTIC SELF-REPRESENTATION AND TERMINAL ILLNESS IN MARK MORRISROE'S AIDS SELF-PORTRAITS

FIONA JOHNSTONE

> "There is no better way to know death than to link it with some licentious image"
> —Georges Bataille.

Mark Morrisroe's 1989 Polaroid *Untitled (Self-Portrait)* is an unflinching portrayal of the thirty-year-old artist in the last few days of his life, taken shortly before he passed away from complications related to AIDS. Shot in black and white and captured from an elevated viewpoint on the ceiling of the sick room, it presents Morrisroe lying naked in bed, his upper body supported by pillows and his angular limbs arranged against the faded floral sheet. The covers are pushed aside to expose the painfully emaciated frame that functions as visual shorthand for the advanced stages of AIDS: his chest is hollow, ribs visible, stomach concave, and legs and buttocks reduced to barely-covered bones. This wasted body is echoed by domestic detritus that litters the surfaces adjacent to the bed: an assortment of soft drink bottles, half-empty coffee cups, disorderly papers and discarded clothes. Perhaps the most insistent aspect of the image is the intensity of Morrisroe's gaze, which seems to penetrate the camera lens and emerge from the photographic frame to meet with the eyes of the viewer. Despite its directness, this look is hard to read. It might be interpreted as confrontational or benign, aggressive or indifferent, or, perhaps most compellingly, as the look of a man who finds himself face to face with his own death.

Fig. 6-1 Mark Morrisroe, *Untitled [Self-Portrait]*, 1989.

Morrisroe’s 1989 *Untitled (Self-Portrait)* [Fig. 6-1], is the most frequently reproduced image in a suite of black and treblewhite Polaroid pictures that present the dying artist positioned on a bed or hospital trolley, frequently naked but occasionally draped in a surgical gown that reveals as much as it covers. Attempts to theorise representations of the sick and dying AIDS-afflicted body have tended to stress the essentially objectifying quality of photography (Grover 1995, 354-381; Crimp 2002, 83-107). Morrisroe’s images complicate such a position: the artist is both the object of the camera’s gaze and its orchestrator, arranging his weakening body to best effect and issuing detailed instructions to the friends that collaborated with him on the production of the image. This chapter suggests that these self-portraits should be read not only as a first person documentary account of the artist’s illness and death, but also in the context of the pronounced sensuality and theatricality of Morrisroe’s early work. Accordingly, Morrisroe’s enigmatic gaze might be productively read for traces of latent erotic appeal: this premise is supported by his pose, which echoes that of previous nude self-portraits. Following a brief introduction to Morrisroe and his critical reception to date, the first section of this chapter establishes the “erotogenic” quality both of his early nudes and of the X-ray self-portraits produced during the initial phases of his illness. The latter half of this chapter reads his deathbed photographs as performative erotic self-presentations, drawing attention to similarities with selected works by his contemporary Robert Mapplethorpe, and identifying an iconography of bondage that simultaneously conveys submission to the material reality of his illness and self-determining mastery of his own image.

Mark Morrisroe

Morrisroe's early life offers a sensational narrative of parental neglect, teenage prostitution, and a serious gunshot wound that left him permanently crippled and suffering from chronic pain. Born in Boston in 1959, he was raised by a depressed, alcoholic single mother (Morrisroe often claimed that she was also a prostitute and heroin addict, although this, like many of Morrisroe's stories, is unsubstantiated). He left home at sixteen, sleeping with men to raise the rent for his apartment. At the age of eighteen, he was shot in the spine by a client, and was forced to spend several weeks recuperating in hospital. Doctors diagnosed Morrisroe as unlikely to walk again; with characteristic willfulness, he regained full mobility. The resulting limp only added to his notoriety among certain sections of the New York art scene; Pat Hearn, his friend, gallerist and executor of his estate, has described how Morrisroe would "wobble, with much presence, into every social gathering […] When he was not looking, he was being looked at. His clumsy gestures and whining voice commanded the attention of those around him" (Hearn 1995, 59). His limp also made him extremely vulnerable, a trait many of his friends considered endearing: as one recalls, "Half your job as his friend was to watch that he didn't fall on his face. He was always falling on the ground" (McPhillips 2001, 110). The chronic pain suffered by Morrisroe as a result of the shooting meant that he would often spend weeks at a time confined to bed; he was thus well practised at working under physical and emotional conditions that would ordinarily present a substantial challenge to creativity. Morrisroe's accident also meant that unlike many other young New York artists of his time, he was acutely aware of his own mortality long before AIDS became a central feature of that world. These early physical limitations allowed Morrisroe to develop methods of working that would be invaluable when the artist decided to record his own experience of a terminal and total bodily decline.

Recent scholarship on Morrisroe stresses the theatrical qualities of both the man and his work: Linda Yablonsky describes an artist who "seems never to have started a day without a role to play", Fionn Meade notes "an obvious and overt theatricality to Morrisroe's portrayal of himself and his friends", and José Esteban Muñoz labels the work a "melodrama" (Yablonsky 2010, 298; Meade 2010, 134; Muñoz 2011). David Joselit's 1995 essay, "Mark Morrisroe's Photographic Masquerade", has been particularly influential in arguing for an understanding of Morrisroe's practice as a "performance of self" (Joselit 1995, 66), and in linking Morrisroe's well-documented habit of self-mythologizing to his complex technical interventions into the development and print processes. Curiously, Morrisroe's deathbed self-portraits remain largely uncommented. Whilst the concepts of "performance" or even "performativity" (Butler 1993) must be handled sensitively in relation to images of terminal illness, Morrisroe's last Polaroid prints undeniably convey a strong sense of theatrical self-presentation. As one of Morrisroe's former tutors at the Boston Museum School observes:

> Mark was a drama queen, so that was his final gesture: being a drama queen. To make art of his death…And you have to admire him for doing something that no-one else had done; looking at a horror with an aesthetic purpose. (Hudson 2012, 78)

Both the drama and the aesthetic impact of Morrisroe's deathbed self-portrait arguably derive from its erotic subtext and its engagement with the art-historical tradition of the nude, a genre explored in some detail by Morrisroe in his early work, especially (although not exclusively) in association with his practice of self-portraiture.

"Erotogenicity" and the Materiality of the Print: Early Self-Portraits and Nudes

Morrisroe's early self-portraits frequently depict the artist in erotic or sexually suggestive poses. One of the best known of these, *Sweet Sixteen: Little Me as a Child Prostitute* (c. 1984) [Fig. 6-2] clearly refers to his early career in sex work, and was allegedly intended for use as a business card. It portrays the young Morrisroe reclining naked across a bed, his legs spread wide, one arm caressing his inner thigh and the other supporting his head as he gazes languidly into the lens. The nude artist also faces the camera in *To Brent (Self Portrait Taken To Answer Sex Ad, Summer 1980)* (c. 1982) [Fig. 6-3], posing in the shower with one arm raised out of frame to activate the shutter. This interpretation of Morrisroe as a sexual subject is borne out by countless other Polaroid self-portraits of the artist posing naked or half dressed, lounging on beds, posturing on a wooden chair, toying with an erection or modelling a brassiere and stockings. Collectively, these early images provide a context of youthful eroticism that render Morrisroe's final self-portraits—produced just five years after *Sweet Sixteen*—particularly poignant.

When he wasn't taking pictures of himself, Morrisroe turned his camera on his friends, a photogenic group of young artists and performers including Steve Tashjian (aka Tabboo!), the Starn Twins, and Jonathan (Jack) Pierson. Again, these subjects frequently appear naked or half dressed: it has been said that Morrisroe was constantly trying to persuade people to take their clothes off (Lebovici 2010, 231). His appreciation for the human form stands out in his numerous male and female nudes: bodies stretch, twist and contort themselves into gorgeous, sinuous shapes framed by dramatic shadows, made both strange and beautiful through Morrisroe's studied manipulations of the negatives and prints. Many of these images cite established art historical precedents: *Young Pia Howard* (1982) suggests Degas' bathers, while the textile drapery over the bathtub in *Untitled (Mario)* (1986) recalls David's *Death of Marat*. Others reveal a formal interest in the relationship between the human form and its surrounding space: *Figure Study* (1985) shows a body of indeterminate sex folded head in hands atop an upholstered chair, the curve of the spine dissolving into the contours of the furniture.

Fig. 6-2
Mark Morrisroe, *Sweet 16.*
Little Me as a Child Prostitute, 1984.

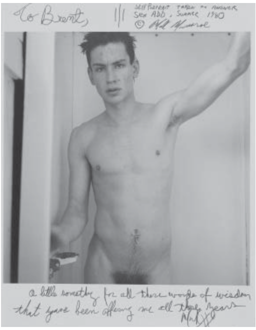

Fig. 6-3
Mark Morrisroe,
Self-Portrait (to Brent), 1982.

An atmosphere of luxuriant sensuality is evoked not only by Morrisroe's subject matter, but also by the material physicality of the prints. Many of his works were treated by the artist as objects of exchange, to be used for marketing purposes (like *Sweet Sixteen*) or handed from one friend to another as gifts or love tokens. Part of this exchange process involved inscribing the margins of prints with dedications and other texts: for example, the hand-scrawled message on *Self-Portrait (To Brent)* reads "To Brent, a little something for all those words of wisdom that you've been offering me all these years, Mark xx”. The margins were also used as a space for experimenting with coloured inks that might later be applied to parts of the image. Initially matted out in commercial exhibitions, these subsidiary marks are now treated as an important part of the work, revealing Morrisroe’s painterly approach to the medium and tendering a ghostly remainder of the artist’s own tactile presence.

The materiality of Morrisroe’s prints is in part achieved as a result of his elaborate method of working with the photographic negative, known as the “sandwich” technique. This labour-intensive process involves producing two negatives (one colour, one black and white), which are then layered together and developed as a single image. The self-portrait *Sweet Sixteen* and a version of *To Brent* were both produced in this way, in addition to approximately 350 other works and a large number of nude figure studies. The process produces a densely textured, almost luscious print, rendering human flesh as a palpably tactile surface that is soft, warm and inviting. The degree of handling required also means that such prints are often marked with rogue flecks of dust, fine lines of hair, and, most significantly, the artist’s own smudged fingerprints; like his marginal scribbles, Morrisroe considered these indexical traces to be an integral part of his style. In *Rose’s Back* (1983), Morrisroe has placed a digit on the negative, causing the resulting fingerprint to swirl and loop around the woman’s lower back and undulate across her spine and shoulders. As if to stress the significance of this personal mark, Morrisroe has retouched the fingerprint with ink, drawing attention to the way in which his own flesh is embedded in the structure of the photograph.

Elisabeth Lebovici writes of the “erotogenicity” of Morrisroe’s sandwich prints; this Freudian term denotes the way in which erotic potential is distributed through the whole body, with pleasure experienced by the internal organs as well as by more obvious external sensory receptors such as the skin, lips and genitals (Freud 1962, 49; Bersani 1995). For Lebovici, Morrisroe’s “erotogenicity” can be felt in the “insidious sexual pulse throbbing through each and every one” of the sandwich works (Lebovici 2010, 232). Also following Freud, Elizabeth Grosz has drawn attention to the distinction between the sexual drive, which is object-directed, and erotogenic desire, which instead of objectives has a series of layered intensities (Grosz 1995, 196). It is evident that Morrisroe’s figure studies fall into the latter category: his nudes are less often configured as objects of desire than as composite spaces where photographed flesh fuses with the material traces of the artist’s own tactile engagement (Joselit 1995, 79).

Imag(in)ing Infection: X-Ray Photograms

When Morrisroe's health started to deteriorate, he began to experiment with the photogram, a medium that required neither a camera nor a model, and could therefore be worked on in the makeshift darkrooms that he constructed during his increasingly frequent stays in hospital. A photogram is produced by placing an object or image on light-sensitive paper that is then exposed, resulting in a shadow-image where areas that have received no light remain white, and areas that have been exposed through transparent or translucent objects take on a tonal range of greys. Using his X-rays as photogram "negatives", Morrisroe experimented with adding colour to the development process. The most captivating of the X-ray based photograms include a triptych of lungs tinted in pinks, yellows and inky blues, the dyes seeping from the respiratory tissues into the darkness of the body like a slowly spreading tumour (*Untitled (Triptych)*, c.1987) [Fig. 6-4]; and a frontal exposure of the chest which marks out the lung chambers in blocks of cyan and magenta and halos the body with an unearthly yellow radiation (*Untitled*, c.1987). The prints are unambiguously self-portraits, authorised by the institutional inscription of Morrisroe's personal details (name, date of birth and hospital number) in the top right corner of the image. Vivid and gorgeous, these pieces seem strangely out of place in a corpus of work that emerges from an encounter with terminal illness.

Morrisroe was clearly captivated by the potential of the X-ray as a source material, acquiring a vast personal collection of X-ray images of various body parts belonging both to himself and to other people. Morrisroe's enthusiastic response to the medium is described in his partner's memoirs:

> Once the doctor showed Mark his X-rays revealing that he had pneumonia. Mark's response was "THAT'S A MASTERPIECE!" He took it, added some of his concocted color photo chemicals, and made the X-rays into beautiful images. (McPhillips 109)

The prints offer a compelling illusion of intimate access to the artist's body. Experienced "in the flesh", they provoke a powerful desire to reach out and touch the image, and by extension to make physical contact with Morrisroe himself.

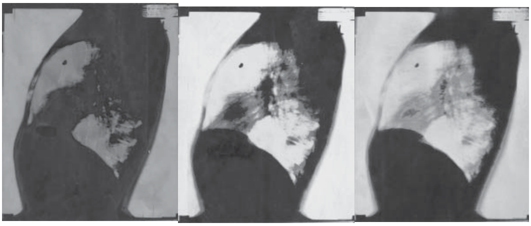

Fig. 6-4
Mark Morrisroe, *Untitled [Triptych]*, c. 1988.

In a much-quoted passage in *Camera Lucida*, Roland Barthes describes the relationship between viewer, photograph and referent as a fantasy of deferred tactile engagement. There is an almost erotogenic quality to the rhythms and cadences of Barthes' text, which seems to throb, pulse and caress the reader, mimicking the palpitations of light from imaged object, to photographic paper, to the eyes of the viewer:

> The photograph is literally an emanation of the referent. From a real body, which was there, proceed radiations which ultimately touch me, who am here; the duration of the transmission is insignificant; the photograph of the missing being, as Sontag says, will touch me like the delayed rays of a star. A sort of umbilical cord links the body of the photographed thing to my gaze: light, though impalpable, is here a carnal medium, a skin I share with anyone who has been photographed. (Barthes 1981, 81)

Barthes' conceptualisation of the photograph as an index or literal emanation of the referent is frequently linked to claims about the documentary value of the photograph. For example, the art historian Rosalind Krauss describes indexicality as one of "the inherent features of the photograph", designates the index a "repository of evidence" (thus emphasizing the "undeniable veracity" of the photographic image), and pronounces the photograph "a literal deposit of the real itself" (Krauss 1977, 59, 64; Krauss 1985, 31). In the catalogue for a major 1985 exhibition of surrealist photography, Krauss and her co-curator Jane Livingston address the close relationship between the photograph and the camera-less photogram (or rayograph, to use the term coined by Man Ray, who made the medium his own). Krauss and Livingston conclude that the photogram makes photography's perceived relationship to the real doubly explicit:

> As the unmodeled residue of the thing's outer form registered through a simple photochemical action, the rayograph surpassed the camera-produced photograph in its univalent transformation of the real object into a sign or trace. (Livingstone 1985, 128)

Like the photograph and rayograph, the X-ray or radiogram "fixes" an indexical trace of its referent in two dimensions; accordingly, Morrisroe's X-rays might be assumed to display the "truth" of his fragile body. Yet their brightly coloured hues quite clearly challenge any notion of their facticity as medical documents.

The X-ray has a long history of associations with erotic and emotional intimacy. In her book on the cultural history of medical imaging, Bettyann Kevles notes that "from almost the day of their discovery, X-rays had been connected facetiously, frivolously, sensuously, pruriently, and seriously with sexuality" (Kevles 1995, 120; Cartwright 1995). The first X-ray image to be published was of a woman's hand with a wedding ring clearly visible on her skeletal figure; in the decades that followed (until scientists confirmed the dangers of excessive exposure to X-rays), the X-rayed female hand became "a fetish object par excellence" (Cartwright 1995, 115), given by women to loved ones as tokens of affection. The potential of the X-ray for erotic intimacy is explored in Thomas Mann's novel *The Magic Mountain* (1924), set in a tuberculosis sanatorium in Switzerland. The inhabitants of the sanatorium each carry a miniature pulmonary X-ray in their wallets like an "identity card" (Mann 1946, 241); the novel's protagonist treasures a "portrait" of the woman with whom he is in love, that depicts "not her face, but the delicate bony structure of the upper half of her body, and the organs of the thoracic cavity, surrounded by the pale, ghostlike envelope of flesh" (ibid., 348).

Metaphors of intimacy and privacy persist in relation to the X-ray even in the late twentieth century. A short story by the French writer and photographer Hervé Guibert (who died of AIDS-related complications just two years after Morrisroe) draws attention to the similarities between the X-ray and the nude:

> Several years ago in the flap of a portfolio, I came upon an X-ray of the left hand side of my torso. I stuck it onto the glass of the French window opposite my desk. The light passed through this blueish network of bony lines and blurry organs as through a piece of stained glass, but by placing this X-ray where anyone could see it (neighbors as well as visitors), I was displaying the most intimate image of myself—much more intimate than any nude, one that contained an enigma, and that a medical student could easily decipher. (Guibert 1996, 65)

Like the most erotic of nudes, the X-ray is both intimate and enigmatic, concealing and revealing in equal measure. It is paradoxical that despite its claim to familiarity, the X-ray gives very little information about the individuality of its subject. Guibert's description of his own X-ray could easily be applied to one of Morrisroe's images, suggesting that the intimate "truth" promised by the X-ray is no more than a fantasy.

Naked or Nude? Late Polaroid Self-Portraits

Many of Morrisroe's final Polaroid self-portraits appear to make use of well-rehearsed visual platitudes of AIDS victim photography (Grover 1995; Crimp 2002), emphasising the artist's shockingly debilitated condition. One image dramatically crops the composition to exclude Morrisroe's head and upper body, focusing on his skeletal thighs, buttocks and emaciated torso to almost fetishistic effect. Others depict Morrisroe curled foetus-like upon the bed, his fragile form illuminated by a single ray of sunlight, or crouched on the floorboards, naked apart from a length of medical tubing taped to his right buttock, hugging his knees to his chest like a terrified child. Less than six months before Morrisroe's death, in the autumn of 1988, AIDS activists gathered at New York's Museum of Modern Art to protest against the display of a series of images taken by the photographer Nicholas Nixon, documenting the gradual deterioration and death of a young man with AIDS by the name of Tom Moran. The pictures bear more than a passing resemblance to Morrisroe's self-portraits; Nixon typically portrays Moran alone, his features obscured by heavy shadow, and his clothing removed to emphasise his dramatically wasted form. Activists criticised Nixon for representing people with AIDS as socially isolated and monstrously disfigured objects of pity, and argued for the importance of promoting affirmative images of HIV-positive individuals as socially, professionally and politically active subjects. In contrast to the activist response, professional art critics were generous in their praise for Nixon's AIDS series. The photography critic for the *New York Times* effused:

> The result is overwhelming, since one sees not only the wasting away of the flesh…but also the gradual dimming of the subjects' ability to compose themselves for the camera. What each series begins as a conventional effort to pose for a picture ends in a kind of abandon; as the subject's self-consciousness disappears, the camera seems to become invisible, and consequently there is almost no boundary between the image and ourselves. (Grundberg 1988, 37)

The truth-value of the photograph is here conceived in spatial terms as directly proportionate to a lack of distance between viewer and image; in turn, this results from the subject's lack of ability to "pose". Equating selfhood with control over one's own representation, this reading of Nixon's images also assumes that death is inevitably characterised by a lack of control over both.

At the level of iconography, Morrisroe's images echo Nixon's in appearing to depict a man no longer strong enough to compose himself for the camera. Projecting a fantasy of total disclosure, Morrisroe's expiring form is invested with an aura of incontrovertible facticity that is difficult to reconcile with a reading of the artist as consummate self-performer. Structurally these works have little in common with the constructed quality of his sandwich prints or photograms; these images have not been manipulated at the level of the negative (an impossibility due to the instant process of Polaroid film), written on, smudged with fingerprints, coloured with inks, or otherwise worked over. Yet despite these images' intimations of an unmediated and "authentic" subject, there is something playful about Morrisroe's slight smirk, and a glint of mischievousness in his gaze that cannot fail to be noticed by anyone already familiar with his work.

This tension is well expressed in a remark made by Sur Rodney Sur, interviewing Rafael Sánchez, an artist friend of Morrisroe's: "The Polaroid of Mark, shot from above …my God, to bare yourself so. And all the while thinking of a good pose" (Sánchez and Sur). In his response, Sánchez recasts Sur's opposition of disclosure and "pose" in terms of "looking like death" and "doing a pin-up shot":

> That picture…knowing that you look like death, and doing a pin up shot, like Marilyn for Playboy, is probably one of the most complicated gestures by any artist. He really faced it. (Sánchez and Sur)

What makes "doing a pin-up shot" whilst "looking like death" such a "complicated" gesture? As the historian of medicine Sander Gilman has shown, the ill body is often marked as ugly (Gilman 1995, 51-66). Morrisroe's self-portraits suggest that to the contrary, the sick body can be beautiful and beguiling, pursuing this evocation of desirability even to the point of death.

The juxtaposition of looking like death and doing a pin-up shot, or of "baring oneself" and "posing", might be recast in terms of the art historical distinction between the naked and the nude. In Kenneth Clark's well-known formulation, nakedness implies embarrassment and vulnerability, whilst the nude denotes a body that is "balanced, prosperous and confident" (Clark 1956, 1). The naked is actual, a sign of material reality;

the nude is an idealisation, "the most complete example of the transformation of matter into form" (ibid., 23). Morrisroe's exposed yet self-possessed body, somehow both concrete and idealised, complicates this position. More recent thinkers have challenged Clark's categories: John Berger suggests that whilst the nude is subject to pictorial conventions, to be naked "is to be oneself" (Berger 1972, 54; Nead 1992, 12-16). Yet Morrisroe is arguably no less "himself" for arranging his body in imitation of the visual conventions of the male nude: one might even argue that the nude is the state in which he seems most *fully* himself. Morrisroe's body destabilises any clear division between the two categories: naked, it attests to the unavoidable finitude of its sickly materiality; posed nude it levels with the viewer's gaze and communicates Morrisroe's steadfast assurance that the body, unwell though it might be, is still his own.

In critical discourse of the mid-1980s, the pose is regarded as an essential tool for deconstructing dominant ideologies and power relations. In a 1985 essay, Craig Owens suggests that posing can constitute a strategy of "mimetic rivalry", allowing the subject to appropriate official discourse by imitating it and thus casting doubt upon its authority (Owens 1992, 201). The pose has also been proposed as an empowering response to surveillance, able to transform the objectifying experience of being observed into the personal pleasure of being watched; Owens quotes from an essay on the self-display of punk women for whom "to strike a pose…is to pose a threat" (Hebdige 1983, 86; Owens 1992, 202). Morrisroe's adoption of a pose is a challenge to the passive position that the dying subject is conventionally assumed to inhabit.

The power of the pose is made explicit in another photographic self-representation of an HIV-positive artist: Robert Mapplethorpe's iconic self-portrait with skull-topped walking cane, taken the year before his own death in March 1989. Mapplethorpe directly faces the camera, his right hand grasping a walking stick decorated with a death's head whose skeletal contours mirror the artist's own pale and wasted face. Clad in a black polo neck, his torso disappears into the dark studio backdrop, so that his head, hand and skull-topped stick appear to float disembodied and ghost-like. Like Morrisroe, Mapplethorpe's gaze meets with that of the viewer; this has been interpreted by more than one critic as a comment upon the insufficiency of the photographic medium for conveying the experience of dying. In his essay "Imagining Sadomasochism", the photography critic Richard Meyer writes: "Robert Mapplethorpe confidently meets, even defies, the gaze of his own camera as though to signify the radical insufficiency of photography to narrate the experiences—and vulnerabilities—of the sentient body" (Meyer 1990, 76). In Meyer's reading, the photograph crucially signifies anger as well as illness: through its very theatricality, Meyer suggests, "the image asserts Mapplethorpe's authority over his self-representation" (ibid., 75). Whilst both artists use the power of the pose to neutralise assumptions of victimhood, Mapplethorpe's self-portrait conveys considerably more gravitas and statesman-like dignity than Morrisroe's raw and confrontational images. The affective power of Morrisroe's images is arguably far greater than that of Mapplethorpe's, expressing not only artistic authority but also intense and heartrending vulnerability. Contrary to Meyer's assertion, photography is not necessarily a "radically insufficient" medium for the task of giving voice to the sick and dying body; Morrisroe's own 1989 *Untitled (Self-Portrait)* offers the possibility of a visual language that communicates both creative control and physical weakness.

The "Intrinsic Theatricality" of S&M

All of Morrisroe's deathbed images discussed thus far were taken in the artist's home, an apartment in a condemned building in Jersey City, an apt metaphor for the artist's own dilapidated state. A further group of previously unpublished images appears to have been taken in a hospital environment; all four images show Morrisroe dressed in a surgical robe and positioned on a trolley-bed, surrounded by medical paraphernalia. These prints have been subjected to a deliberate process of destruction and decomposition by the artist, achieved by peeling apart the Polaroid print and negative whilst the film is still wet and sensitive, allowing patches of white light to leech over the film's surface and eat away at the image. Two are sick room shots taken in quarter profile. A third [Fig. 6-5], taken from behind, depicts Morrisroe almost entirely concealed beneath the bed sheet, glancing back over his shoulder with just a tiny amount of skin revealed by a gown that casually falls from his shoulder. Given his previous predilection for nudity, this striking detail suggests striptease; a spotlight angled at Morrisroe's head gives weight to this reading. The fourth image [Fig. 6-6] also supports an interpretation of the hospital bed as a stage for Morrisroe's final performance. Morrisroe lies on his left hand side, his torso twisted so that the lower half of his body turns away from the camera, and his upper body rotates towards it; this awkward movement is necessitated by the attachment of his right arm to an intravenous drip. His shoulders are covered, but his hospital garment (tied at the neck) falls away revealing thighs, buttocks, and genitals. Depictions of the human body from this angle frequently signal erotic vulnerability, but the image does not convey weakness so much as a sense of sexual challenge. The composition draws on an iconography of bondage that Morrisroe had explored in several earlier works.[1] *Untitled* (c. 1981) shows the head and shoulders of a person entirely encased in cellophane and packing tape, a black tube protruding from a hole where the mouth is assumed to be, whilst *After the Laone (In the Home of a London Rubber Fetishist, Dec 82)* (1982) voyeuristically depicts the twist of Morrisroe's back and buttocks as he lounges on his right-hand side, his left arm draped back across his body.

Morrisroe's hospital-bed images share some striking similarities with a collection of Polaroid self-portraits taken by Mapplethorpe between 1972-3 (Mapplethorpe 2001). In several of these, the artist's otherwise naked body is girdled with a slim black strap that encircles his torso and buttocks. In one image, Mapplethorpe's left flank is exposed to the camera, his elbow pointing away from his body as his shoulders pivot and torso twists, forced into this rotation by the position of his hands, which are bound behind his back. The pose echoes Morrisroe's: both men share the same distant gaze that mixes mild contempt with a will to be desired. Selected prints by Mapplethorpe in this series address the sadomasochistic theme explicitly, whilst others are only softly sensual: like Morrisroe, the young Mapplethorpe poses on rumpled sheets, his body foreshortened, the images cropped or captured from unusual angles. This is not to suggest Mapplethorpe as a necessary influence on Morrisroe; their work embodies two very different approaches to photography, elegantly summed up in a review article written by Vince Aletti for the *Village Voice*:

> Morrisroe revelled in the overheated and the handmade—in the serendipitous funk of crudely fixed Polaroids and photograms that looked like Man Ray on angel dust. Mapplethorpe strived for classic elegance, for balance, for sophistication, and a flawless finish. (Aletti 2000, 67)

Yet the two men nonetheless do share a certain aesthetic, in that both engage with an established tradition of depicting young male bodies in positions of semi-erotic vulnerability.[2]

Fig. 6-5
Mark Morrisroe,
Untitled [Self-Portrait], c. 1988.

Fig. 6-6
Mark Morrisroe,
Untitled [Self-Portrait], c. 1988.

Mapplethorpe's 1978 image of himself clad in black leather, buttocks bare, bent over with a bullwhip inserted into his anus as he twists back to look at the camera offers another strong comparison with Morrisroe's late works. As Meyer points out, in this image Mapplethorpe is "not only simultaneously submissive and dominant, vulnerable and authoritative, he is also explicitly authorial" (Meyer 1990, 67). Mapplethorpe's dual role as photographer and erotic participant mirrors the mobile subject position implicit in sadomasochistic practices: "the masochism of the gay male body is…as much invitation as intimation, as much erotic object as dominating subject, as much psychic "bottom" as penetrating 'top'" (ibid.). Echoing this, Leo Bersani has proposed that sadomasochistic bondage practices might be a means of attaining "erotogenicity", denoting a "degenitalizing of erotic intensities" (Bersani 1995, 23). Bersani suggests that Freud appropriates the notion of sexuality to describe phenomena that until then were not thought of as sexual: Freud, Bersani writes, "coerced the sexual into describing what I would call a certain rhythm of mastery and surrender in human consciousness" (ibid.). It is this "rhythm of mastery and surrender" that describes the simultaneously expression of passivity and active self-representation in Morrisroe's 1989 *Untitled: (Self-Portrait)*.

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Notes

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[1] Thanks to Teresa Gruber at the Mark Morrisroe Archive for drawing my attention to this.

[2] For example, see Mantega's paintings of Saint Sebastian (c.1456-90), or Michelangelo's *Dying Slave* (c.1513-15).

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CHAPTER SEVEN

"TREBLE EXPOSURE": FISSURED MEMORY IN EVA FIGES' FICTION

MARILENA PARLATI

Unfolding Lives and Bodies

Michel Foucault's work on the archaeology of Western knowledge and on the moulding of subjects and subjectivities on the part of porous, ever-present, and internalised powers still functions as an unrelenting trademark of contemporary formulations of identity. Truly enough, as Elaine Campbell (2010) suggests, the French historian turned philosopher has often been attacked for his lack of an ethics (Vintges 2001, 166), as well as for his awkward obliteration of the matter of gender in his reconstruction of the history of Western fashions and re-fashionings of normative bodies.

On the other hand, Judith Butler's continuous rereading of Foucault may serve to provide correctives to an over-simplistic reading of any discursive construction of embodied individuality:

> The position that the body is constructed is one that is surely, if not immediately, associated with Michel Foucault. The body is a site where regimes of discourse and power inscribe themselves, a nodal point or nexus for relations of juridical and productive power. And, yet, to speak in this way invariably suggests that there is a body that is in some sense there, pre-given, existentially available to become the site of its own ostensible construction. What is it that circumscribes this site called "the body"? How is this delimitation made, and who makes it? Which body qualifies as "the" body? What establishes the "the", the existential status of this body? Does the existent body in its anonymous universality have a gender, an unspoken one? What shape does this body have, and how is it to be known? Where did "the body" come from? (Butler 1989, 601)

In this chapter, I intend to read some of Eva Figes' works by intercepting both Foucault's and Butler's conceptions of and on the body and discourse. In my view, even Butler's critique of Foucault needs to be interrogated and corrected, not least through her own recent work on precarious lives; I also wish to demonstrate that the perspectives offered (and required) by critical disability studies must be adopted in attempting any analysis of the ways in which the purported “anonymity” and “universality” of bodies are represented. If “the body” is a site, can it be “circumscribed” and “shaped” as though it were, not only gender-neutral, but also age- and health-neutral? How is a Foucauldian “unfolding of life” to be reformulated to include and consider the multiple interruptions and interpellations variously presented by illness, pain, disability, ageing, and impending death?

Discourse on subject “positionality” (Alcoff 1988), on normative and “normate” forms of embodiment (Davies 1997, 2010, 2013) has been the focus of numerous recent literary, biographical and auto-biographical works of “faction”, which have attempted to test and expand the borders of both *life* and *writing*. Remarkably, one registers a bend towards pathography, the fictional representation of illness and of otherwise complex forms of embodiment. In the perspective adopted here, that turn verges to comprise *death* and/in *writing*, which, in Jacques Derrida’s view, is the other side—the excluded, exorcised side—of what he terms “otobiographies” (Derrida 1988). In a similar key, Louis Marin suggests that self-narration corresponds to autobiothanatography, both being necessary and yet “personal and incommunicable” (Marin 1991).

I contend that many of the fictive works written by Eva Figes, née Unger, point to the very possibilities of narrating life, ageing and death and are haunted by gaps and duplications, by narrative, typographical and at times grammatical lack of closure. In *Days* (1974), *Nelly’s Version* (1977), *Waking* (1982), and *Ghosts* (1988a), she seems intent on a thoughtful, if not gloomy, protracted experiment with memory and oblivion, with the page as well as with the bodies whose ageing and failures she obsessively sounds out.

Locating Figes

Since her death in 2012, work on Eva Figes, her memoirs, her fiction, her position as public intellectual in post-war Britain, has indeed gained momentum. A dedicated polemicist, she wrote highly acclaimed feminist revisionary books, such as *Patriarchal Attitudes: Women in Society* (1970) and *Sex and Subterfuge: Women Novelists to 1850* (1982), in which she addresses the many forms of stereotypical limitations women, and women writers in still deeper senses, have had to confront with in the West. While *Patriarchal Attitudes* caused clamour and was highly praised, her fiction has been less unanimously well received. For many scholars, among her most remarkable works are those related to her experience as a German-Jewish child "transported" to Britain in 1939. That forced relocation has undoubtedly had a profound impact on Figes: she started working through her traumatic memories of "Little England" and of the silenced disappearance of her Berlin grandparents in her first novels, *Equinox* (1966) and *Konek Landing* (1969). Yet, it is in the programmatically autobiographical *Little Eden. A Child at War* (1978), *Tales of Innocence and Experience. An Exploration* (2004), and in the harshly polemical *Journey to Nowhere* (2008) that Figes discovers and gives voice to her own traces of the Shoah and to her bitter, disillusioned, views on the state of Israel.

In the words of Julia Tofantšuk (2007, 13), though, any rigid classification of this writer is pointless:

> From outside, she has been…classified as a modernist and a representative of the British avant-garde, and, bearing in mind her ethnic background, it would have been easy to attach another label: Jewish…[Yet] this writer goes against the grain of "pigeon-holing".

While supporting this view, which must take into account the variety of forms and styles Figes adopts in her works, I find it feasible to read her writing from the perspective of trauma and memory studies, and decode the numerous lacunae which haunt her fiction as symptoms of repression and of its provocative return on the page, as Susana Onega has repeatedly done (2011, 2012). Seen from this angle, Figes certainly shares the predicaments of "post-memory" so carefully envisaged by Marianne Hirsch:

> The "post" in "postmemory" signals more than a temporal delay and more than a location in an aftermath…Postmemory shares the layering of these other "posts" and their belatedness, aligning itself with the practice of citation and mediation that characterize them, marking a particular end-of-century/turn-of-century moment of looking backward rather than ahead and of defining the present in relation to a troubled past rather than initiating new paradigms. Like them, it reflects an uneasy oscillation between continuity and rupture. And yet postmemory is not a movement, method, or idea; I see it, rather, as a structure of inter- and trans-generational transmission of traumatic knowledge and experience. It is a consequence of *traumatic recall* but (unlike posttraumatic stress disorder) *at a generational remove*. (Hirsch 2008, 106; my emphasis)

Thus, Figes seems to me embroiled in the controversy over the question and questioning of witnessing with which Primo Levi was so deeply concerned:

> We, the survivors are not the true witnesses…we survivors are not only an exiguous but also anomalous minority…Those who did so, who saw the Gorgon, have not returned to tell about it or have returned mute, but they are the "Muslims", the submerged, the complete witnesses. (Levi 1988, 83-84)

While never seeing camps, and being carefully protected from the reality following *Kristallnacht* within the relatively safe walls of her wealthy Berlin house, Figes was deeply wounded by the eradication of her memory/ies, of her rooted sense of belonging in and to her country and her native tongue, violently set apart once on English soil. Therefore, it seems to me only appropriate that, even in texts which apparently deal with ordinary lives, at a "safe" distance from the aftermath of the Shoah, this writer always experiments with the frontiers of fiction and addresses the painful theme of the obliteration of the/her past. Her quasi-poetic voice and textual projects do "testify" to what Anne Brewster has beautifully defined a "poetics of memory":

> A writing motivated by the poetics of memory mimics the "origin" effect; it is the movement of proleptic and analeptic reversals…The insistence of repetition creates a condition of hauntedness—*memory* locked together with its supplement, *forgetting*. (Brewster 2005, 401; my emphasis)

In this oscillation between memory and forgetting, in extreme utterances which mimic amnesiac confusion and molecular degeneration, "Figes writes about silences and the breaking of silences" (Verdon 2014). Treading on utterly contentious ground, her writing moves aporistically and offers no solution, no hope, no healing procedure, in fiction so tense that its very status remains trapped in paradox. In the works I will consider, Figes opens textual archives whose legibility and veracity are strenuously defended *and* attacked by the writer herself: it is the act of writing, its technologies, the possibilities of representation it may offer which are targeted. Her first-person narratives, reminiscent of both Virginia Woolf and Samuel Beckett, are lost in repetitions and mistaken recollections, and her fictive narrators are unreliable witnesses of their own openly fractured identities. And yet, while at a loss for chronological and topographical certainties, her solitary "heroines" are almost invariably gendered in the feminine:

> The heroism of the allegedly gender-neutral liberal individual contrasts sharply with the structural requirement of his emotional and pragmatic support by a feminine Other, who is dependent yet capable, decorative yet hardworking, and subsumes her own life projects under those of her husband, family, or, increasingly, her workplace or the patriarchal state. (Heyes 2007, 4)

Obsessively, Figes' female narrators and protagonists, her forlorn multifarious "I's", oscillate between home and away, the "here" of loneliness and ghostly sites and the "there, then" of nostalgic pasts whose very existence is repetitively put at stake. The status of biographical, and *auto*-biographical, narration demands belief, but that belief is continuously menaced by the ferocious grammars of self-construction and/in annihilation Figes manages to construe. Caught in between the requirements of traditionally normative femininity and motherhood and undulating requests for personal freedom, Figes' fiction and characters may well document the validity of Deleuze's contention: "forgetting is the impossibility of return, and memory is the necessity of renewal" (Deleuze 1988, 108).

Proper Names: Nelly's Version

> "He watched my hand slide across the page as I signed a false name and address in the hotel register". (Figes 1988, 9)

Nothing could seem more realistic. Formally, this statement lacks no logic, no grammatical particle. Yet, that allegedly false signature mobilizes a vertiginous dance of "proper names", names owned and acknowledged as such, or names rejected and annulled:

> There are two simultaneous demands governing the proper name…on the one hand, a requirement of untranslatability and unreadability, as if the proper name were nothing but pure reference, lying outside of signification and language; on the other hand, a requirement of translatability and readability, as if the proper name were assimilable to the common noun. (Lévesque, in Derrida 1985, 93)

As Claude Lévesque stated in his introduction to a Roundtable on Translation at the University of Montreal in 1979 centered on Jacques Derrida's work, propriety and property are related to the key question of naming and signing "*one*-self", as the single, monolithic, "heroic" Subject of grand and petty narratives. In *Nelly's Version*, the *all-but-one* narrator records her thoughts and memories in two notebooks which aim at systematizing, checking, controlling life/narration.

> I have decided that, if I cannot control my sleeping hours, I must at least try to establish a workable shape and pattern in my waking ones. To that end, I have begun to keep a systematic record in my new notebook…It will provide *indisputable evidence* in case I become the victim of further mental aberrations. I can refer back to it, *if my memory continues to be unreliable* in the future. (Figes 1988b, 67; my emphasis)

Yet, as Derrida suggests on numerous occasions, legibility is a strongly controversial issue; in Figes, the violence of naming—and being named, called upon, inscribed within set patterns—is hauntingly repeated throughout a text which falters on its own undecidable nature: “Already I cannot be sure that it is entirely accurate, but at least I have begun at the beginning” (ibid.). On the one hand, Figes plays on the necessity of holding on to “all these bits of the distant past” (ibid., 43); on the other, she shows her narrator painstakingly rewriting and, by so doing, discovering the sheer pointlessness of writing. Indeed, the aporia of representation is on this writer’s agenda.

While “hiding” in a comfortable hotel in an unnamed small British village or town, “Nelly” wanders around and encounters bits and pieces of a life she can’t acknowledge as her own. The novel repeatedly stresses its materiality, as when she records buying and starting her first notebook, and when she discovers another archival location, the community library, whose sense completely escapes her.

> I did the only possible thing, and pulled out a book at random. It fell open at a crack in the binding and I read the first lines of a paragraph which began near the top of the right-hand page:
> *He watched my hand slide across the page as I signed a false name and address in the hotel register.* (1977, 84)

Books—and writing hands—follow each other, repeat each other, sliding in a literal *mise en abîme* of Borgesian-like phantasms: what books does Nelly read? What does she write? Who does she write for?

> I have only to read the other notebook to understand that she undoubtedly was rather mixed up and confused. *She* seems to have been quite lost. I have now decided to try and impose some kind of narrative coherence on my life, or what is left of it...*I* can find no meaning in it. The whole thing slips through my fingers like water or sand. (1977, 186; my emphasis)

"I is an other", as Rimbaud famously stated: this "I" is lost in the crevice between her two notebooks, which form the two parts of the novel. In the middle of unaccounted-for crimes, such as robbery, assault, arson, "Nelly-narrator" is re-traced by her husband and son, and trapped back into her familial ties and possessions. Name included.

Her second notebook (163) opens with a hint at recovery: "I had been ill. I was told I had been very ill, though I had absolutely no memory of it" (165). The contours of Nelly's illness coincide with her duplicitous "version", a prolonged, tiresome re-visioning process which strips her of any coherence and leaves her and her reader clueless.

> There must surely be something abnormal about a mind with such a conspicuous lack of retentive power, whether of purpose, emotion, or memory. I write as a corrective to this defect, though *I can never be sure to what extent I am falsifying*. Everybody should have a story which is coherent, with a certain consistency. (187; my emphasis)

In *Nelly's Version*, that corrective is sadly rooted in amnesia, false testimony, or, in my view, in fictive molecular degeneration which closely—and not too metaphorically—resembles Alzheimer's disease. Traumatizing and dramatically totalizing lack of retention, in Jane Wilkinson's words, the "country of this disease", is mapped through the progressive annihilation of all measures and rhythms:

> Within its country/ies, multiple temporalities overlap, form warps of time and frozen moments as fragments of the past invade and replace or complicate the present. Space is mobile and disjointed. Texts open to unfamiliar dimensions of existence: absence, but also complex forms of presence. *Syntaxes, rhetorics and structures are transformed.* (Wilkinson 2014, 104; my emphasis)

The French historian Pierre Nora has suggested that "modern memory is, above all, archival. It relies on the materiality of the trace, the immediacy of recording, the visibility of the image" (Nora 1989, 13). He also asserts that this material "exterior scaffolding" enhances memory by offering it a "*prosthesis*-memory" (my emphasis). Nelly's notebooks purport to be such prostheses, yet they confuse and render traces opaque, transforming all the information Nelly has to offer into unreadable palimpsests of repetitive, therefore meaningless utterances. The usual passage on the narrator's signature at the hotel is reported again in the concluding pages of the novel; yet, no typographical mark, no italicised passage is adopted to help readers decipher its function and its sense:

> But I found it difficult to take anything in. He watched my hand moving across the page as I signed a false name and address I read, and thought, how stupid of me, I must have had this book out before. Or perhaps I was simply reading the same pages a second time, because of my lack of concentration. *I had failed to comprehend what it was all about, and could not make out the plot, even if I had read it before.* (Figes 1977, 208; my emphasis)

To complicate things further, and outline the predicated position writing takes in this novel: in the house she is supposed to acknowledge as her home, "Nelly" discovers the message "*I am leaving you*" —— presumably addressed to a cold, estranged husband —, mockingly archived on a not-exactly-permanent material support: toilet paper. And carefully, obsessively recorded on it, "the same message appeared with meticulous *consistency* along each perforation" (1977, 191; my emphasis). For Figes, written words as/and memory prostheses are doomed to irreversible liquefaction.

Textual Somatics: *Days* and *Waking*

From a certain standpoint, Figes' fiction always assumes a quasi-autobiographical stance. Her fictive first-person narrators might be writing what J. P. Eakin calls "relational autobiography" (Eakin 1999, 60), troublingly resting on a self which is "truly plural in its origins and subsequent formation". Far from being transparencies for a totally dismissed view of the self as monarch, as always-already there, the novels by Figes I work on here encounter and unfold what Rose has aptly defined "somatic individuals".

> Selfhood has become intrinsically somatic—ethical practices increasingly take the body as a key site for work on the self. From official discourses of health promotion through narratives of the experience of disease and suffering in the mass media, to popular discourses on dieting and exercise, we see an increasing *stress on personal reconstruction through acting on the body* in the name of a fitness that is simultaneously corporeal and psychological. Exercise, diet, vitamins, tattoos, body piercing, drugs, cosmetic surgery, gender reassignment, organ transplantation—for "experimental individuals" the corporeal existence and vitality of the self have become *the privileged site of experiments with subjectivity*. (Rose 2001, 18; my emphasis)

In Figes, what "matters" is indeed bodily matter, fragmentarily recorded in its unstoppable unrolling. If one recalls Butler's question:

"Which body qualifies as 'the' body?" *Days* and *Waking* do not pivot around prescriptive and inscriptive habits aimed at transforming "it", but rather around a passive registering of the devastating workings of time and disease.

Days (1974) is a bleak novel which focuses on "aging and its discontents" (Woodward 1991). The setting is a hospital room, in an indefinite city, at an indefinite time. Its protagonist lies in painful immobility due to an unclarified illness from which she seems to be convalescing. With her, a bed, and a chair which remains empty until it is occupied by the nameless patient's spirit. And, in between, sparse recollections of other times of useless waiting, of lying without resting, of burning loneliness. Days and space are always the same, always repeating themselves, tearing morsels of life and health out of an already painfully weak body: "A person must be strong enough to inhabit his or her own story" (Figes 1974, 118). In Stein's words, in this novel:

> There is no way out of what remains to be a verbal, a physical and a mental prison…The past in this novel is a limiting presence; it does not liberate but keeps the narrator imprisoned in a world of stifling memories…the feeling of suffocation…cannot be overcome and the ghosts of the past are not laid to rest. (Stein 2012, 83-84)

Waking (1981) is another intense and sparse novel which records the allegedly unmediated fluxes of thought of yet another nameless narrator. Seven mornings in her life, with the same house functioning as connecting grid; seven differing encounters with various forms of embodiment. As a child, she scans herself: "I pull the bedclothes over my head. This is my house, dark, secret and warm. It smells of my body" (1981, 11). As an adolescent, the novel records a harsh confrontation with parents perceived as unaccountable and unbearable:

> Last my night I wrote in my diary, "I do not want to forget, ever, what it feels like to be me now." That is why I keep writing things down. I am changing, I know that. I will continue to change, and some day I will be old, a woman like my mother. Except that *I do not want to turn into somebody like her*, that is why I write it down, to remind myself, how it was, how it is now, everything so intense, nothing absurd or childlike. (1981, 27-28; emphasis)

Figes allows a short "summer" of physical beatitude to her narrator (ibid., 51), only to revert soon to a vivid enactment of the body as "site of contestation" (Grosz 1994, 19). Her bodies—never pliant and docile—are rather met and recounted in their "dys-appearance", at the temporal and textual crux when their ordinary "functions" are interrupted, as Drew Leder suggested in a text which unwittingly foreshadows the positions of many disability studies scholars (Leder 1990, 92).

> Nothing is quite as it should be. I wake back into a world in which everything has become uncontrollable, is going wrong in unforeseen ways. My body, for instance, it has suddenly become a dead weight, something with which I am at odds...I rise each morning with *a layer of detritus, dead matter, old skin clinging to me, an invisible web of dust, cobwebs, falling hair and the skeletal outline of dried leaves which I cannot shake off.* (Figes 1981, 61; my emphasis)

As Woodward states, *Waking* deals with a daughter's "memory-dreams" which are "tactile" and deeply connected to birth, embodiment, death (Woodward 1991, 105). Thus, when she states, "In a sense I am born each morning" (Figes 1981, 76), this narrator, eventually confused by an ailing memory, repeatedly configures herself as a woman, a wife, a mother, who has been playing roles. This experimental novel may fruitfully enact the "noncoincidences of the self" Anne Brewster describes:

> If repetition is constitutive of memory, then a writing which investigates the poetics of memory will deploy tropes of repetition in the project of mimicking the discursive structures and strategies of memory. It will take as its basis the idea that repetition is non-original, that beginnings are recursive and self-doubling—an event or feeling exists in close proximity to prior events and feelings, haunted by histories that are momentarily held at bay, forgotten. A poetics of memory might investigate the retroactive constitution of beginnings; the foldings, unfoldings and refoldings of images, feelings, narrative fragments. (Brewster 2005, 397-398)

Tracing Death: *Ghosts*

Waking re-enacts the primal scene of birth, and of age and loss, in beginnings which "fold and refold" until they reach the limit of what Shlomith Rimmon-Kenan (2006, 245) refers to as "[a] disintegrating body [which] may threaten the very possibility of narration." In its final section, Figes obliterates punctuation, mimicking a brain which sees and addresses ghosts, in a poetic attempt at representing the moment of death and the encounter with a long-lost and forgotten mother:

> It is coming nearer, she has come for me, she has not forgotten, she holds a torch in her hand, mamma, she has come back to the seashore and I am

> safe, now that she has come to fetch me, pick me up and carry me home". (Figes 1981, 88)

In *Ghosts* (1988c), Figes sets out on a lyrical investigation of the undiscovered country of death, its relics, its shadows: "Oh, my lost ones" (1). Unsurprisingly, past, present and future haunt this text, again inhabited by lexical repetitions, by semantic scantiness and fragmented typography. Figes' language implodes in this search for mimicry, this "modernist" allegiance to stream-of-consciousness technique. And again, what is under the lens is the complex relation between bodies and written memory, in the inversions and folded duplications which infest both: "My body which is not my body, sweating into the sheets. My life which is not my life, waking up round me, as the walls become faintly visible" (2).

Another mother-daughter relation is at stake, and again the text becomes an occasion for "diving into the wreck" (Rich 1973) of the intricate interplay between memory and forgetting. The narrator loses touch with herself and her past: "I write: what was I doing last year? Or the year before, at this time? A blank. Nothing" (7). But the immersion into oblivion once again includes an interrogation of the possibilities of writing through a poetics of memory: "Is a 'self' possible when the ability to construct narrative through memory is broken?" (Basting 2003, 88). The other memories involved, those of the real "stranger", of the narrator's mentally invalid mother, are nostalgically and unsuccessfully conjured, but adamantly resist representation:

> I cannot believe it is too late, even now, or that the damage is irreversible. I cannot believe she will not respond to her own flesh and blood. That, if those dry hands once stroked my child's flesh, they will not know it now…she does not know who I am. (Figes 1988c, 60)

An unspecified form of vascular dementia founders memories, and annihilates bodies in a specular manner: one woman, the mother, slides into total cancellation; her daughter, another mother, soon follows along the same unfolding path leading nowhere.

> We used to come here as children, she says, and she begins to tell me things I cannot remember. This woman who sits beside me, resting, has memories we do not share. I listen, astonished, to a past I cannot remember. Even though we lived it together. I look at her and know that her present life is unknown to me, but that the past too should not be really shared is *disturbing*. (110; my emphasis)

Figes is concerned with archiving histories and herstories, and imagines “the body” as a “trebly exposed” brain, trembling under an excessive mass of stimuli, which eventually coincides with death.

> I see only resemblances, shadow on shadow, the ghosts in the living. My sense of the actual is changing…Are things really here at all…are any of us present? I think of my brain as a film negative that has been doubly, perhaps trebly, exposed. (133)

In a beautiful, delicate inquiry into death, into *the* coming death of her very old, disabled, beloved mother, Hélène Cixous writes (of) a “denarration” (Richardson 2006, 87). She anticipates her mourning and yet nostalgically partakes in what she calls “le temps d’avant la fin”, “the time before the end”, an intensely valuable interim of “splendor” (Cixous 2006, 19; my translation).

In *Ghosts*, where no such positive trace can be found, Figes ambitiously attempts to capture the instant of death, *in* writing, *of* writing. The exposure she refers to is the utter coincidence of “What one calls life—the thing or object of biology and biography—…with [that] something that would be its opposable ob-ject: death, the thanatological or thanatographical” (Derrida 1985, 6). In her effort, in this text but also in her other works, she powerfully scans through practices of embodiment and of representation, uncovering the dangers and traumas of illness and the voids opened up by death (Lévinas 1991). I conclude with the words of *one* self, one body, which, more literally than others, has experienced and recounted the rigueur of impending, unassailable silence, the same silence that marks Figes’ fictional investigations.

> I must now be done with writing…I will soon be stripped of language and memory…I am on the cusp of a new world, a place I will be unable to describe. It is the last hidden place, and marked with a headstone. (De Baggio 2003, 207) [1]

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Notes

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[1] I wish to thank Jane Wilkinson for introducing me to the cultural relevance of Alzheimer's patients, their plight and their powers.

CHAPTER EIGHT

THE UNBORN UNDEAD: A JOURNEY WITH A BI-FOLD BODY

JOANNE “BOB” WHALLEY

> *This is not a story with a happy ending. As this chapter progresses I will be discussing my multiple miscarriages and I feel it only appropriate at the outset that I prepare you for the conclusion. This is not a story of redemption, and I do not type this with a child nursing at my breast. I remain as barren as I have ever been. I just wanted you to be prepared.*
>
> *This is a story about grief, about sorrow and about things which refuse to let go.*

This writing navigates an engagement with difficult knowledges by using personal disclosure as a resource for opening up possible understandings surrounding miscarriage. In 2012, after an ultrasound scan determined that my pregnancy was not ongoing, I entered a phase of what is termed “expectant management”, which describes a waiting period after miscarriage for the tissue to pass out naturally. In this month of waiting, I struggled with the knowledge of carrying a dead foetus with me / inside of me / alongside me, in a backdrop of quotidian comings and goings. As the foetus was without a heartbeat it was clearly no longer living, but nor was my foetus fully dead either, being flesh folded within flesh. The hormones produced by the pregnancy continued to impact upon my daily existence. I continued to experience morning sickness, I still felt pregnant. Perhaps because my body refused to surrender the gratuitous cells, and as a means to navigate the confusing sensation of grief I experienced, I developed a brief and burgeoning relationship with my “monster in utero”, reframing my obstinate and wayward cells as a zombie. Rather than opt for the immediate surgical removal, we decided, my zombie and I, to wait for “nature to take its course”. In the narratives that follow, I attempt to offer a different perspective on the zombie body, and tell of its “doing”. My inquiry situates itself in the experience of expectant management using the zombie as a conceptual tool to confront unthinkable knowledge: the loss of a viable pregnancy. It describes a personal kind of zombie experience, and concerns the ways in which the zombie can be experienced *with* and *through* the body.

It is my intention that this writing should speak to the possibilities afforded by the conceptual zombie. It is important that I make clear the zombie I invoke here is the zombie of the horror film, specifically the post-Romero zombie, a revenant that feeds on the living and does so mindlessly. It is not my intention to invoke the philosophical or p-zombie, a thought experiment devised to explore models of consciousness. Thus, when I refer to my zombie as a means to conceptualise elements of my experience, it is important to reinforce that these experiences grew out of my body, they were the result of the embodied process of carrying the dead within me, and reflect the sense of doubling this resulted in. My zombie offers the opportunity to think sideways about embodied and situated cognition, and seeks to encourage narratives between the body and the world, through the use of my own body as agent. These narratives are not intended to decentre or degrade the profound emotional impact that miscarriage has upon a body, not only on the woman herself, but also on her partner, family and friends. Neither are they an attempt to articulate "trauma narratives" to diminish the experience towards "recovery". Rather, they situate knowledges by seeking to understand how the performance of the zombie through my own body might begin to articulate narratives of grief positioned within a feminine terrain.

As with any text which offers grief as a central plank of the narrative, the reader might be expected to allow for a certain level of subjective experience to bleed its way into the writing. This is certainly the case here, but it should also be recognised that the inclusion of a subjective first-person narrative is a deliberate methodological strategy. The inclusion of my body within the thesis is intended as a way to allow space for embodied experiences to serve as means to develop useful strategies of resisting normative narratives around miscarriage. While grief might well conform to a particular pattern, one's experiencing of it is singular. Although I might have gone through all five stages of loss and grief, these manifested themselves within my body, and the affective states generated are thus unique to my psychoneuroendochronologic process. When I write of "feeling" something, I mean this to be read as both emotional and humoral.

In a consideration of how this might be achieved, it might be appropriate to start with a confession:

> *I am not a zombie, and have never been a zombie, but once I carried a zombie with me for four weeks.*

The disempowerment of abjection is something that has been negotiated in the writing of Julia Kristeva, in which she positions the abject as "neither subject nor object…neither inside nor outside" (Kristeva 1982, 135). Those female expulsions rendered too messy for safe consideration further problematises the experience of miscarriage; especially the missed miscarriage which refuses to makes itself visible through the usual outward signifiers. As Kristeva has it, the abject does not "respect borders, positions, rules" rather it disturbs "identity, system, order" (Kristeva 1982, 4), all of which describe my experience of being "with zombie".

Central to filmic zombie lore is the fear of infection; the scratch or bite of the zombie is a guaranteed death sentence, which will render up the wounded to the hordes of the walking dead. Zombies are the abject made flesh, or rather; they typify that which is already abject in the flesh. They embody infection and putrefaction, they reduce the human experience to the very basic drives, and they terrify because they are what we will all inevitably become, they are the outcome of the thousand shocks that flesh is heir to. Zombies shuffle and rot their way towards us, and we can see echoes of the fear of their abjection in the writing of Kristeva:

> Loathing an item of food, a piece of filth, waste, or dung. The spasms and vomiting that protect me. The repugnance, the retching that thrusts me to the side and turns me away from defilement, sewage, and muck. The shame of compromise, of being in the middle of treachery. The fascinated start that leads me toward and separates me from them. (Kristeva 1982, 2)

This anxiety of the dead walking, the horror of that which we will become is offered a specifically gendered take in the writing of Barbara Creed when she explores the concept of the "monstrous-feminine" in her book of the same name, *The Monstrous-Feminine: Film, Feminism, Psychoanalysis* (1993). This anxiety is evident when she references the corpse (including the zombie), stating that "[i]t signifies one of the most basic forms of pollution—the body without the soul. As a form of waste it represents the opposite of the spiritual, the religious symbolic" (Creed 1993, 10). This sense of "pollution" is doubtless part of why my un-expelled foetus began to position itself as a zombie within my internal narrative. It is perhaps inevitable that my thoughts turned to the concept of parasites, and to monsters-in-utero, and to the horrors and pleasures that these concepts afford. The prospect of carrying something without a soul speaks to all those maternal fears of giving birth to a monster, concerns which have been explored across countless films (*The Omen*, *I Don't Want to Be Born*, *The Brood*, *Rosemary's Baby*, *It's Alive*, *Basket Case*—the list goes on). These narratives of the monster-in-utero play into the primal concerns of loss; loss of control of the body, loss of agency as we move from women to mothers, and of course, loss of the pregnancy itself.

Although not considered a classic of the genre, overshadowed by the more cerebral *Rosemary's Baby* (1968), I have always felt that Peter Sadsy's *I Don't Want To Be Born* (1975) captures the anxieties of the monster-in-utero with a certain camp clarity. Starring Joan Collins and Donald Pleasance, this was a film I remember from the late-night television of my youth, and in many ways it offered a template for my own future maternal anxieties. It follows a fairly typical route, with a stripper played by Collins rejecting the advances of a dwarf with whom she works, only to be subsequently cursed for spurning his advances. Nine months later, she delivers a twelve-pound baby which proceeds to murder all around it, including his mother, before finally being exorcised of his demons. The narrative brings together all the tropes of the monster-in-utero, while also reinforcing a mid-seventies anxiety over female sexuality. The child is conceived out of wedlock by a sex worker, and although she "settles down" by marrying a wealthy Italian businessman, the promiscuity of her past is offered the physical form of her monstrous issue, and she suffers the ultimate punishment, first losing her husband, and finally her life.

These filmic fears articulate the natural anxieties of impending motherhood, and thus cease to resonate once there is a catastrophic shift in the pregnancy. As soon as I became aware that the child I was carrying was no longer alive, I was no longer subject to those same fears. There is nothing left to fear when the child inside you has died, so the narratives of monster-in-utero no longer apply.The horror film is a deeply sexualised genre, with the invocation of gender anxiety wedded into the landscape of horror filmmaking. Certainly, *I Don't Want To Be Born* reinforces a range of normative gender tropes. Indeed, the sexualisation of female characters is often offered as a rationale for the dismissal of horror from mainstream acceptance, thus maintaining it as a ghetto genre, one that is less valued than other filmic forms. But to accept this, is to miss the resistant strategies employed by many genre pieces. Women are hunted down throughout these films, but the redemptive end tends to position the female protagonist as triumphant:

> If some victims are men, the argument goes, most are women, and the women are brutalized in ways that come too close to real life for comfort. But what this line of reasoning does not take into account is the figure of the Final Girl. (Clover 2005, 77).

This Final Girl does more than simply survive, she thrives. She is the active agent who prevails over the monster, and most significantly, the men, because “[n]o male character of any stature lives to tell the tale” (Clover 2005, 78). As such, the masculine is usurped as “[t]he Final Girl has not just manned herself; she specifically unmans an oppressor whose masculinity was in question to begin with” (ibid., 81). Given the deeply gendered world of the horror film, the shift of my baby from monster-in-utero to zombie opens up further narratives of resistance. Unlike the Final Girl, I was not able to achieve a redemptive third act. The death of the baby robbed me of agency, and rendered me non-generative. Arguably, this is because I ceased to be the protagonist in the narrative of my pregnancy. Instead of occupying the role of the Final Girl, my expectant management rendered me mute. I functioned not as character, but as location; from that point on, my role was scenographic: I am the shopping mall which houses the zombie. My walls have been breached, and I must simply wait to see how things might play out.

It is very rare that zombies are sexed creatures; they function as the opposite of the vampire. Both are undead, both rise to live again, but it is the vampire that sustains its libidinal urges. The vampire differs from the zombie in that it uses death to transcend its former humanity, and to cast off its relationship to the human as something unwanted. In most literature and filmic representations, vampires no longer have any need for the animal hang-overs of sweating or defecating; even breathing is too mechanical for these elevated creatures. Unlike the zombie, the vampire transcends putrefaction, and is elevated to something that moves beyond the human bodies it feeds on. Vampires are allowed to divest themselves of the abject; as a result, they become pure. Zombies are afforded no such luxury. They wear their former humanity, with no hope for transcendence. Instead, they shuffle around becoming less and less human, as they become more and more abject. As Miller observes:

> Unlike vampires, the zombie is not afforded life everlasting. Rather they are confined to a body which, although invulnerable to pain and able to withstand most damage, cannot regenerate. Instead, they continue to rot away to bones, but craving human flesh all the while. (Miller 2014, 198)

Indeed, just as the vampire becomes *more*, as its true essence is revealed after death, the zombie narrative runs counter to this. It becomes less, it is diminished and is forced to live its afterlife in a state of advancing deterioration. It is in this state of deterioration that more and more of the originary referent of the self is shed, and it is this reduction that is central to the zombie mythos, or more specifically, central to the experience of living in a world overrun by zombies.

In the pilot episode of AMC's *The Walking Dead* (2010-present), the audience is introduced to a post-apocalyptic world in which a zombie-plague has wiped out most of the human race. Much like Danny Boyle and Alex Garland's *28 Days Later* (2002) we are introduced to this world through the eyes of a recently awakened hospital patient. This plot device allows for the audience to slowly build an understanding of the radically different world they find themselves witnessing. These are worlds without pity, in which grieving becomes almost impossible. Pragmatically there is simply not the time to successfully mourn and still fight for survival. It is in this context that Rick Grimes (Andrew Lincoln) is rescued by Lennie James' character Morgan Jones. Despite the fantastical nature of the world being presented, at the centre of this pilot episode is a character study of a widower failing to grieve. The world which he finds himself inhabiting is too chaotic to give space to the process. As a result, he is stuck in the first stage of the Kübler-Ross model, unable to accept that the revenant that makes a nightly pilgrimage to his front door is no longer the same woman who bore his equally traumatised son. The director of the episode, Frank Darabont, costumes Jenny Jones (Keisha Tillis) in a nightgown, semiotically positioning her in the attire of the bedroom, wearing a costume of intimacy usually reserved for one's partner. Her willingness to walk through the night in this outfit points to the upending of normative convention, and reminds the viewer that something is not right here. But this notwithstanding, James' character is unable to dispatch his zombie-bride, and instead occupies a limbo state, no less uncertain than that of his wife. This sense of denial, the idea that this cannot really be the world inherited by the characters, runs through the pilot episode, and while the other five stages of grief are played out through the remaining episodes and the remaining seasons, it is Morgan Jones and his wife that I hold onto as the model of zombie grief. I hold onto. That is a telling turn of phrase, one that I did not initially choose to reference my own experience of zombie grief, but one that is wholly apposite.

Carrying my zombie baby was a month in which I longed for the natural, yet unfinished process of shedding cells, to have some outward signifier of my own shift in states: from pregnant to unproductive. Within my body, my zombie-baby had been similarly marked as incomplete: flitting between significations of being part of my flesh, firmly secured in my belly, and yet still an object of abjection. It was an unexecuted instruction and half-done: a thing both not-yet and no-longer. Kelly Oliver, who writes broadly about Kristeva, describes "[t]he not-yet-subject with its not-yet, or no-longer, object maintains “itself” as the abject (Oliver 1993, 60).

Simply put, I found myself longing for the abject. I wanted my leaking and messy body, I wanted:

> A wound with blood and pus, or the sickly, acrid smell of sweat, of decay, [that] does not signify death. In the presence of signified death—a flat encephalograph, for instance—I would understand, react, or accept. No, as in true theater, without makeup or masks, refuse and corpses show me what I permanently thrust aside in order to live. These body fluids, this defilement, this shit are what life withstands, hardly and with difficulty, on the part of death. There, I am at the border of my condition as a living being. (Kristeva 1982, 3)

Such cleaving from my body would have enabled me to move towards grief; instead, I remained in a hinterland, embodying an undecidable. For Kristeva the recognition of the infant’s own body begins a process where they separate themselves from others, in order to develop borders between “I” and other, “Not I”. In discussing the abject response of nausea to curdling milk, Kristeva states that:

> “I” want none of that element, sign of their desire; “I” do not want to listen, “I” do not assimilate it, “I” expel it. But since the food is not an “other” for “me,” who am only in their desire, I *expel* myself, I spit *myself* out, I abject *myself* within the same motion through which “I” claim to establish myself. (Kristeva 1982, 3)

This sense of “expelling myself” takes on a very different meaning for the woman engaged in the expectant management of a missed miscarriage. The inability to “spit out” my zombie *in vivo* rendered me curiously mute, temporarily unable to clarify my own selfhood. It is not just the failure of the pregnancy, but also the stasis which prevented a moving forward that was at issue. My body, already a site not a character, was held in the first stage of the grieving process. The decision to emerge, or rather, be expelled from the union between mother and child, was denied. If the newly born infant cannot differentiate where one body begins and the other ends, imagine the body which houses the zombie-baby. Not only can it no longer tell where one ends and the other begins, it is no longer certain it is even a body belonging to a self with any agency. Instead it is a storage unit, housing that which cannot (literally) be borne. To enter into any understanding of where the borders of the body lie, those borders must be maintained. As Creed observes, “[t]he concept of the border is integral to the construction of the monstrous within the horror genre” (Creed 1993, 11), and it was during this period, that I waited until "[m]y body extricates itself, as being alive, from that border" (Kristeva 1982, 3).

Although I started from a position of difficulty, of recognising a certain awkwardness in attempting to write through this experience, this difficulty does not spring from discussing the loss of a pregnancy. That is, of course, a difficult thing to process. However, as stated in the introduction, I do not view the words on these pages as opening up a therapeutic space. Rather the difficulty comes from staying on topic, and in part, from the broader context of zombie interpretations. My zombie was certainly nothing extraordinary in zombie science: a creature that flitted between the boundary lines of life, exploring a twilight existence. Nor are my zombie journeys without their antecedents; I am not alone in trying to navigate this strange walking, carrying with me a remnant of the biological past. In Margaret Atwood's short story "Kat" written for the *New Yorker* (1990), Kat, an "avant garde" fashion photographer has a cyst removed, only to find it contains both hair and teeth and "[s]he'd made the doctor promise to save the thing for her, whatever it was, so she could have a look" (Atwood 1990, 38). Following the surgery, she keeps the cyst in a jar and names it "Hairball". This teratoma, a homunculus of sorts, has been Kat's unknown partner in life up to the point it is removed. The storage and naming of Kat's "little man" becomes her resistance against the urge to expel and deny something/someone who had shared the same blood vessels with her. Strangely, my adventures in pregnancy—for that is what I am surfacing here—have resulted in the generation of my own teratoma, a dermoid cyst which developed after my fourth miscarriage, and now occludes my left ovary. Like Kat's "Hairball", it contains superfluous matter (in my case, only teeth), but for now this new passenger remains nestled inside me instead of residing in a jar.

It seems that my body is confused, expelling the things I want to keep, and keeping the things that have outstayed their welcome. My teratoma continues its slow journey in darkness with me, and I must congratulate my body, despite its confusion, in gladly nurturing the same kinds of cells that also produce human eggs. But this doesn't feel of the same order as my zombie-baby, mostly because I have no urge for it to be expelled. The teratoma has grown, twisted, and connected itself through veins and nerves. It feels more permanent, more like it belongs. It feels at home. In the case of my zombie-baby and my body's unwillingness to expel the newly dead foetus, I remained in the thrall of the abject, and it was with this shift that what no longer grew inside me became a zombie. It was a secret shared between the two of us, myself and my zombie. It was the opposite of those public articulations of post-miscarriage grief seen in the "memorial YouTube videos for lost pregnancies" (Lupton 2013, 2). It became a lacuna, a gap between life and death situated in a space which had heretofore been entirely ignored in my daily existence. Perhaps my imagining of the foetus transformed was a way of internalising the grief I felt, especially as for over a month I had nothing to grieve over; there was no emptying of my uterus, experientially I remained pregnant. And it was not just the lack of a productive miscarriage which made it difficult for me to know how best to negotiate my loss. As Lupton observes:

> For such tiny organisms, the unborn bear an enormous ideological, political, moral, ethical and effective weight. Embryos and foetuses have gained increasing visibility in the public domain to the point that they have become fetishised cultural icons and subject of fervent contestation over meanings and ontologies. (Lupton 2013, 2)

And I knew that what I was experiencing was a daily occurrence, something which is difficult to mourn because to do so vocally is to run the risk of indulging in mawkishness. Or at least that was my fear. The grief that I am writing about is a small one. It's a commonplace one, but it is grief nevertheless. The thing about loss is that it is contextual. It lives inside of you, and only you can feel it. You can offer up words to try to frame it to people kind enough to ask how you're doing, but you know that the words are always wanting. And once those words are out, they sound so small, so insignificant. For a long time, it made me feel guilty to think of what I was feeling as grief, or loss. I mean, it's not as if anyone died, I mean, not really. Or, not real. Not a real person, just the idea of a person. Although the zombie that I held inside me is long gone, the lingering narratives remain. The questions they raise are sufficient to explore a twice-told tale beset by a bifold body, in an attempt to describe a zombie folded and carried alongside its obverse companion.

Measuring one grief against another is a terrible idea, but the simple action of speaking your grief out loud makes that measurement an inevitability. How can you say something aloud without it being compared in the ears of the person you are speaking to with something, someone they have lost? And for a person that has walked around the world, learned words, had experiences, thought thoughts, fought wars, loved and lost, they have to have had bigger losses than the shedding of a simple collection of cells, no matter how many times you might have unwillingly spit them out of yourself.

This is a story about a small grief. A grief so small it isn't even person-shaped. Perhaps this is why my baby became a zombie.

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CHAPTER NINE

"PERDITA UPON HER LAST LEGS": MARY ROBINSON IN SICKNESS AND IN HEALTH

CHRISY DENNIS

See Robinson forget her state, and move,
On crutches tow'rds the grave [1]

These lines from William Gifford's satirical poem, *The Baviad* (1794) encapsulate a decade of scurrilous and scabrous attacks on Mary Robinson (1756-1800) at the latter part of the eighteenth century. Tom Mole suggests that the rise of celebrity culture in the late eighteenth century "was from the beginning a multimedia phenomenon" (Mole 2009, 2). This is particularly apparent when examining the different textual and visual portrayals of Mary Robinson (1756-1800). Robinson, once a star actress, then later courtesan, poet, novelist, polemicist and essayist, was one of the first celebrities to be idolised and adored by the general public. It was this public obsession that opened up a space for competing textual and visual representations of Robinson which either extolled her as a woman of beauty and a style icon, or portrayed her as an extravagant, overly sexualised and dissolute woman. More interestingly perhaps, for this chapter, are the portrayals of Robinson as a diseased prostitute and latterly, a crippled wretch. As Tim Fulford points out, "whether as actress or courtesan, fashion icon or radical writer, it was Robinson's body that defined her" (Fulford 2002, 9). Despite the appellation of English Sappho and her prolific publishing output during the 1790s, Robinson is best remembered as a courtesan and mistress of many high-profile men such as the Prince of Wales (latterly George IV), the Whig politician, Charles James Fox and the war hero, Banastre Tarleton. Robinson's body was increasingly used as signifier for the corruption of the body politic: the antithesis of the John Bull figure commonly used to personify Britain. Satirists regularly composed or created highly sexualised images of Robinson that linked her to high-profile men, positioning her as a prostitute. As Betsy Bolton states, these satires and caricatures can be read as a reaction to the threat of order and stability that Robinson presents. Her "power to attract not one but a range of men raised concerns about political promiscuity and the ideological relations of public men and public women...caricatures and pamphlets used the trope of prostitution to domesticate and degrade the figure of Mary Robinson as public woman" (Bolton 2001, 106). This suggests that it was the public nature of her affairs, rather than the affairs themselves that was problematic. As Bradford K. Mudge suggests, "if what should have remained private became public, then the indignant and the self-righteous would raise their voice in protest" (Mudge 2000, 55). Part of this protest was the creation of the *Perdita* figure (the Prince of Wales called Robinson Perdita and signed himself as Florizel) into which she would become subsumed; her body represented as a commodity that was owned, conquered, boarded and discarded. However, I argue that while these images can be read as signifying the prostitution of politics, they also reflect late eighteenth-century anxieties about the role and place of women. Not least because many of the representations of Robinson make an explicit link between Robinson's lifestyle and her declining health.

The public nature of her affairs, made Robinson baiting a sport for press and satirist alike. Robinson and the other members of the *demi monde* were often portrayed in caricatures that drew on metaphors of sickness or disease. An example of this can be seen in the "INTELLIGENCE CRITICAL and EXTRA-ORDINARY" column of the *Gazetteer and Daily Newspaper*:

> A medical correspondent recommends, that the Perdita, the Dally and the Smally, and other fire-ships, be obliged to perform quarantine before they be admitted to watering places. Some of them have conveyed the plague to Tunbridge, which has proved fatal to many.[2]

The term "Fire-ships", a euphemism for whores and courtesans, is just one of an array of nautical, farming and property metaphors that were used in the press in the late eighteenth century when discussing courtesans, mistresses and prostitutes. The plague can be read in one of two ways, firstly, as venereal disease and secondly as a criticism of the large number of courtesans who followed royalty and the aristocracy to the fashionable spa towns.

The metaphor of shipping, this time of a ship in battle is used in the *Morning Post* in its spoof article in the "Ship News" column which describes Robinson as: the "*Perdita Frigate*...a prodigious fine *clean bottomed* vessel". The piece goes on to say:

> The *Perdita* was captured some time ago by the *Fox*, but afterwards retaken by the *Malden*, and had a complete new suit of rigging when she fell in with the *Tarleton*. Her manoeuvring to escape was admirable: but the *Tarleton* fully determined to take her or perish, would not give up the chace [sic], and at length, *coming along side* of the *Perdita*, fully determined to board her *sword in hand*, she instantly surrendered *at his discretion*.[3]

The comment regarding Robinson’s bottom is a reference to the success of her breeches roles when she was an actress. However, the overall tone of the piece pictures Robinson as a sexual object, one that is worthy of a war between these men. Banastre Tarleton was a British hero of the War of Independence and often pictured with his “sword in hand”. The innuendo here is crude and unflattering and leaves the reader in no doubt that the “capture” of and ownership of Robinson is in terms sexual conquest, but not one of her choosing; she is reduced to the spoils of war between these men. Although interesting enough in itself, when placed against the turmoil of the Constitutional Crisis between 1782 and 1784 it not only demonstrates the anxieties about the state of government but also the influence of this public woman.

Examining the political climate at the time alongside Robinson’s personal life shows that both were in a state of flux and turmoil. Lord North’s government fell in March 1782, following a vote of no confidence because of the loss of America, which left the constitution reeling. Moreover, the eighteenth-century reading public would have been aware that Lord North led the negotiations between the king and Robinson over the return of letters written by the Prince of Wales. The Whig politician, Fox, resigned in July and almost immediately began a liaison with Robinson that was subject to a great deal of public and private scrutiny (Mitchell 1992, 97).[4] However, as Robinson became involved in Whig party politics, the criticism of her became more vociferous. In part, her association with Fox, the most caricatured figure in political life, makes it seem logical that Robinson would appear in many of these caricatures as part of the pillory of the intended subject (Gatrell 2006, 323). However, one particular caricature *Perdito and Perdita—or the Man and Woman of the People* (1782) suggests that the emphasis is on Robinson, rather than Fox.

The caption shows that Fox has been given the masculinised form of Perdita, suggesting that his reputation has been tarnished because of his association with Robinson. Yet, the anxieties about Robinson’s influence are clear too: she holds the whip and is driving the carriage while Fox is reduced to a shambling and ill-kempt figure.

Fig. 9-1 *Perdito and Perdita—*
or the Man and Woman of the People, 1782.

Gillray's *The Thunderer* (1782), however, is one of the most damaging of the caricatures that feature Robinson. At first glance, it would appear that Robinson is not the main subject of the caricature, particularly as the two men, the Prince of Wales and Banastre Tarleton, are presented in the foreground. Robinson is portrayed as a tiny figure impaled upon a spike above the shop doorway. Paula Byrne points out that, "the figure of sexually impaled Mary reveals a clear allusion to the Romney portrait" which was painted during the negotiations with Lord North and in which she is presented as modest and innocent (Byrne 2005, 198). The sign above the door shows that the building is called "The Whirligig" which, as Robert D. Bass suggests was a cage used as a form of punishment by the army to discourage prostitutes (Bass 1972, 202). Robinson's legs are wide apart, her breasts are bare and she declares, "Who would not love a soldier?" This caricature is clearly a public rebuke of Robinson's lifestyle and of her becoming involved in the political realm.

Fig. 9-2 James Gilray, "*The Thunderer*", 1782

The *Morning Post*, which had been among her harshest critics, stated that, "it is to be deplored that she is not the happiest, because she has a heart to be the best; yet to her should be adjudged the highest praise, who in a difficult situation shews, by her sensibility, that she deserves better" (Bass 1972, 202). However, the image which would have been openly displayed in the window of the print shop reinforces previous depictions of Robinson, sex and commerce.

In May 1783, newspapers began to speculate about whether or not Robinson was pregnant and who the father might be. Reports said that Fox made daily visits and that the Prince of Wales, "has made constant enquiries after the health of *Perdita*, ever since that lovely representative of the Cyprian Goddess has been confined with her present indisposition".[5] While Tarleton was almost certainly the father, Robinson's pregnancy provided an opportunity for the press to remind the public of Robinson's past lovers. The implicit criticism of her lifestyle, which was far from chaste, retiring and modest, is clear:

> The *Perdita*...being, it is said, in a state of *pregnancy*, and at liberty to long for *Ribbons* as well as *Stars and Garters*, had recourse to velvet to form the *black stripe* on the *pink* ground. She has since had some manufactured of a beautiful quality. It is supposed by many, this is worn by her, chiefly on the devices of the ancient *Egyptians*, who, when their animals were breeding, laid them on *various coloured rushes*, to produce a *beautiful* race![6]

Gamer and Robinson have noted that the readers of the late eighteenth century read with a high level of sophistication and understood the complexity of the nuances and innuendoes in the various articles and *Intelligences* (Gamer and Robinson 2009, 232). Like the earlier allusions to ships and property, this paragraph dehumanises Robinson and positions her as a brood mare in the Foxite stable.

However, an illness in July 1783 would change both Robinson's life and the representations of her. In the early hours of the morning, Robinson chased after her lover Tarleton who was fleeing the country to escape his debtors. At some point on this journey, it is likely that Robinson suffered a miscarriage.[7] Her subsequent debilitating illness and eventual paralysis would provide a great deal of material for the satirical pen. Robinson's romanticised version of events in her *Memoirs* suggested that

> Imprudent exposure to the night air when travelling, when exhausted by fatigue and mental anxiety, she slept in a chaise with the windows open, brought on a fever, which confined her to her bed during six months. (Robinson 2010, 270)

The idea of Robinson having had a miscarriage is supported by a letter from Lord Pembroke to a friend dated 13 August 1783. Lord Pembroke writes, “Her face is still pretty, but illness has brought on a disadvantageous additional scowl to it; and as to her body, she is quite défaite” (Byrne 2005, 229; Gristwood 2005, 204; Davenport 2004, 141). He goes on to describe Robinson as barely dragging herself along and ends with “[s]he may possibly come about again, but she must not go any more to an Opera on the day of a miscarriage” (ibid.). This is clearly censorious and the moralistic tone is easy to see. Other reports about Robinson varied in seriousness, from mild discomfort to complete paralysis, much of which was rumour and innuendo, and while Robinson remained unusually silent during this period, the papers filled in the gaps.

However, many of these reports were thinly veiled attacks on Robinson’s character. The first news report of Robinson’s illness was in the *Morning Herald* dated 31 July 1783. Henry Bate, the newspaper’s editor, was usually supportive of Robinson, yet he too was unable to resist gossip and innuendo.

> Mrs. *Robinson* lies dangerously ill at her house in Berkley Square; the envious part of her own sex attribute her indisposition to chagrin at the declining influence of her charms; if that be really the case, the name of *Perdita* will soon be too truly applied to this once all-conquering impure!

The juxtaposition of ideas is clear. On the surface, the author appears to sympathise with Robinson—it reports that she is dangerously ill and criticises the gossips that suggest that Robinson is sulking because of her declining beauty. But it is the final part of the sentence that is most interesting; the suggestion is clear that this decline in Robinson’s health, beauty and influence will ensure that Robinson’s reign as the leading courtesan is over. Two days later, on 2 August 1783, the *Morning Herald* reported:

> Mrs. Robinson sis not so bad as was reported; but is still very unwell. Her indisposition is said to be occasioned by her love of gaiety; and her keeping the revels of midnight beyond her strength of constitution.

The report attacks Robinson’s lifestyle with the implication that she should take the blame for her condition. However, Robinson’s illness did not free her from the scourge of the press, not least because many in the eighteenth century believed that the body was the “signature of the soul”: illness was thus often viewed as a signifier and punishment of a dissolute life (Porter 2001, 44). Robinson did not conform to the notions of approved female conduct and so her lifestyle, subjected to public scrutiny, was used as a warning to other women. As we have seen, this was a common thread in criticism of Robinson, but her illness presented the press with an actual, rather than metaphorical, disease to criticise Robinson's conspicuous consumption, and blame her dissolute lifestyle for her malaise. The *Perdita* narrative had changed: the once famous and beautiful woman, who authored herself as an object of desire, would continue to be portrayed through her body, but it was now a broken body. As the *Morning Post* suggests,

> The example of the *Perdita*, which two or three years ago was of the most dangerous kind to the beautiful and the thoughtless of her sex, is now as salutary; a life of wanton dissipation has reduced her to penury and distress; poverty with all its horrors surrounds her; her constitution and the use of her limbs are done; death stares her in the face...To view Perdita *now*, would be a lesson indeed.[8]

The moralising tone is clear, Robinson's illness and eventual paralysis is offered as a warning to all who wish to emulate her—a picture of what will happen if women step outside the boundaries of what was expected.

The *Rambler's Magazine* continued its criticism of Robinson: "[t]he Perdita, who has been ill, mends but very slowly. She is said, from her shattered condition to be unfit for any further service. She is, however, in dock and the colonel is emptying her cargo, and stopping her *leaks*".[9] The metaphor of shipping is used again and as discussed above, carries sexual connotations and mirrors the quotation from the *Morning Post* in that Robinson will be unable to continue as a fêted courtesan, yet it also implies a continued sexual relationship with Tarleton, despite her illness.

Robinson would not completely recover her health, but by the end of January 1784 she had re-taken her place in the fashionable world and would spend the next few months campaigning for Fox. She was a loyal and ardent supporter of Fox and the Whigs alongside Sheridan, the Prince of Wales and the Duchess of Devonshire. The Duchess of Devonshire and Robinson were pilloried in the press for their open support. However, Robinson found herself the subject of more caricatures, scurrilous biographies and malicious reporting. The most damning and damaging was the false and pornographic *Memoirs of Perdita* (1784). The publication was filled with graphic detail of sexual encounters that pictured Robinson as sexually voracious and not particular in whom she chose to satisfy her needs (Lister 1784, iii-iv).[10] The editor/author introduces the *Memoirs* stating that they have been "communicated by *one* who has for several years been her confident, and to whose pen she has been indebted for much newspaper panegyric" (ibid., 1). Lister suggests that Robinson had dictated the *Memoir* herself and that someone close to Robinson had passed it to him and, moreover, this someone was the same author who was involved in writing puffs and praise of Robinson. The advertising for this text clearly placed Robinson's life story with that of the whore biographies that were prevalent at that time. The whore biography was a "new literary sub-genre that developed from the beginning of the eighteenth century, which fits in-between mainstream novels…and libertine literature" (Peakman 2006, ix). These biographies of famous courtesans such as Fanny Murray, Sally Salisbury and Nancy Dawson, were read alongside novels such as Daniel Defoe's *Moll Flanders* (1722) and *Roxana* (1724). In part, the biographies that were produced were "mildly titillating exposés of whores" and many of them were forged (ibid.). Therefore, any forgery of Robinson's biography is not unexpected and as with other 'whore biogrpahies' contained pornographic depictions in order to discredit her further.

In 1784 Robinson and Tarleton faced bankruptcy and the press responded with a number of stories. The *Morning Post* reported that the "Cyprian divinity of Berkley Square is said to be on her last legs".[11] The piece was written as a pun, conflating her disability and her precarious financial situation; however, following this account, a caricature, *Perdita Upon her Last Legs* was printed in the August issue of *Rambler's Magazine*, which portrays Robinson as a diseased and crippled streetwalker.[12]

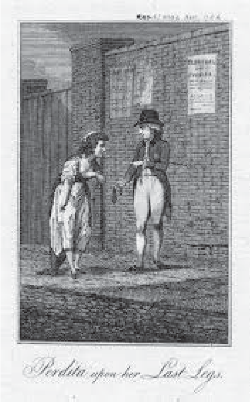

Fig. 9-3 *Perdita Upon Her Last Legs*, 1784.

Roy Porter suggests, "[r]evulsion against the flesh and exposure of its absurdities are deadly weapons in the satirist's scourging of evil and mockery of folly" (Porter 2001, 44). The title of the pun works twofold. First, it refers to Robinson's illness, represented by her thin and shrivelled legs and secondly, it refers to her need for money to survive; the annuities paid by the Prince and Lord Malden, even if paid on time, were not enough to keep her. The caricature portrays Robinson standing on a street corner begging, wearing a low-cut dress, suggesting that she has lost her health and beauty and therefore she can no longer use her body as a source of her wealth. Behind her is a high brick wall on which there are play-bills, a reminder of her once successful stage career and her roles in breeches parts for which her legs were greatly admired. The print suggests that Robinson had been cast-off by the Prince and his friends and shows a downward trajectory, suggesting that as a commodity, she is no longer required or of any value to the men that used to fight over her. What is seldom discussed is the text that accompanied the engraving headed "PERDITA upon her LAST LEGS, or the LAMENTATION of a MAGDALEN".[13] The writer presents the lament as being written by Robinson. The first part discusses the influence her beauty had previously had but suggests that new "conquests are not to be made without beauty's ammunition; and that I fear is almost exhausted!— Disease, afflicted by the rapacious hand of time, is daily pilfering from me some portion of my charms!"[14] The images of war in terms of "ammunition" and "pilfering" refer back to earlier images of the "wars" over Robinson by influential men. The lament goes on to bemoan beauty as "a perishable commodity": when it fades, a woman loses all that it brings.[15] This suggests that Robinson only made conquests because of her beauty, that the sum of her was her body. The negation of Robinson's influence because of her intelligence and wit and the failure to mention her success on the stage and the publication of her poetry, suggests that Robinson was perceived as more than the sum of her body. The piece ends with two lines from the poem "Hans Carvel" by Matthew Prior (1701): "When poor weak women go astray/Their stars are more in fault than they." An irony that would not be lost on its intended audience as these lines are from a ribald poem about a woman who cares more for luxuries than for her husband, but suggests that her ways were predestined.

In order to seek a cure and to escape their money problems, Robinson and Tarleton travelled around Europe. Despite her absence from Britain, the reports continued. The *Rambler's Magazine* reported in September 1784 that:

> Mrs. Robinson has been lately obliged to leave England, for the continent, for the recovery of her health. She has almost lost the use of her limbs, and, upon her journey, was lifted in and out of her carriage. Her disorder is a rheumatic gout of so obstinate a nature that her recovery is doubtful.[16]

Robinson moved from spa to spa, with a prolonged stay at Aix-la-Chapelle, in her search for a cure. However, her time at Aix was not a place of quiet solitude as Robinson's *Memoirs: Continuation by a Friend* suggests that Robinson received many visitors and that:

> Her beauty, the affecting state of her health, the attraction of her manners, the power of her mind, interested every heart in her favour; while the meekness with which she submitted to her fate excited an admiration not less fervent, and more genuine, than her charms in the full blaze of their power had ever extorted. (Brewer 2010, 270)

This challenges the notion of representations of Robinson being defined solely through her body, which the press suggests. Sarah Gristwood suggests that Robinson would have been part of a "culture of the European Spa: the warm salt taste of an iron-rich spring—like a mouthful of blood; the rotten smell of sulphur-rich water; the precision with which a physician might prescribe a daily diet from several different springs, each with its different properties" (Gristwood 2005, 223). After almost two years living on the continent, On 14 July 1786, the *Post* announced, "Mrs Robinson, the once famous Perdita, died a few days ago at Paris". Much of the information for the obituary was taken from the false *Memoirs of Perdita*; therefore, it is easy to surmise that Lister might have written the piece. The obituary praised Robinson's beauty and her genteel manners. However, as with the false *Memoirs*, the piece was full of inaccuracies, which is a common theme in any examination of Robinson's life. Again, this is a piece that adopted a strong moralising tone: "This Lady had she walked in the paths of virtue and peace, would have been an ornament to her sex, and a peculiar happiness to his of whom she was the *better half*".[17] The tone can be linked to manual conduct, but it provides an example of how not to behave, a warning for all women about the dangers of society. Further, in a direct address to the Cyprian Corps, in August 1786 the *Morning Post* added the following verse couplet as "a good natured hint to the Cyprian multitude": "Let coxcombs flatter, and let fools adore,/ Here learn the lesson to be vain no more" (Byrne 2005, 256). Interestingly, Robinson's life is offered up as a lesson to all other women, including the courtesans. The use of lines of poetry, although often badly written poetry, satirises Robinson's position as a female writer, with particular emphasis on her time as a member of the Della Cruscans. Again, these are attacks on her public presence.

Robinson sent a humorous letter in response, playing down her condition as "a trifling lameness". She replied:

> SIR. With astonishment I read in a Morning Post of the 14th instant a long account of my *death*, and a variety of circumstances respecting my *life*, equally void of the smallest foundation. I have the satisfaction of informing you, that so far from being *dead*, I am in the most perfect state of health; except for a trifling lameness, of which, by the use of the baths at this place, I have every reason to hope I shall recover in a month or six weeks. I propose passing my winter in London, having been near two years upon the continent, though not at Paris half the time.

Although Robinson writes in a humorous tone, she does criticise the publication's use of inaccurate biographical information that remains in the public realm. The *Morning Post* did not print an apology or retraction, but they did print her letter. Lister's article in the August edition of the *Rambler's Magazine* further supports the notion that he had written or provided the information for the *Morning Post*. In a section titled "Topics of July 1786", Lister placed a joint obituary for "Mrs. Baddeley and Mrs. Robinson".[18] Unlike his other articles about Robinson, this obituary is rather low-key, baldly stating that she died in Paris. Key to this obituary is the report that Sophia Baddeley, a once-famous actress and courtesan, had died penniless whilst Robinson received "the bounty of her royal lover, who indisputably allowed her an annuity of 500l. a year [and] was enabled to make a stand against the fickleness of her admirers, when beauty began to decline".[19] With this mention of Robinson as a kept former mistress, and despite common knowledge that the Prince often failed to meet his promised payments, the sentiment of this comment suggests that Robinson received enough money to live quietly and she should do so.

In the summer of 1787, Robinson and her daughter returned to Europe, again seeking a cure. This time the two visited St Amand in Flanders. The desperate nature of this visit is evident from the description of the healing mud baths as:

> Those receptacles of loathsome mud, and of reptiles, unknown to other soils, which fasten on the bodies of those who bathe. Mrs Robinson made many visits to these distasteful ditches, before she could prevail on herself to enter them. (Brewer 2009-10, 275)

Despite overcoming her disgust and enduring these baths, they were not a success and Robinson moved back to England in January 1788 and "became reconciled to the calamitous state of her health: the mournful certainty of total and incurable lameness, while yet in the bloom and summer of life was alleviated the consciousness of intellectual resource, and the activity of female fancy" (ibid.). From this period until her death Robinson would enter what was to be a prolific writing period and over the next twelve years she would write several poetry collections—she became lauded as the English Sappho—seven novels, and several essays.

Robinson's change of direction from courtesan to writer did not spare her from the earlier criticisms, not least because of her association with radical thinker and writers such as William Godwin and Mary Wollstonecraft. Robinson's support of radical causes and her increasingly radical writing brought her to the notice of the anti-Jacobin circle who criticised her as a "disconcerting and disruptive presence" (Garnai 2009, 70). William Gifford's *The Baviad* (1791) attacks radical women and their writing calling it "frigid ravings and common-place extravagances" (Gifford 1791, 23). However, whilst Gifford attacks Robinson's work, her critical abilities and her association with Robert Merry, Gifford's most pointed attack is against her body. The lines: "See Robinson forget her state, and move,\On crutches tow'rds the grave," to "Light o' Love" (ibid.) infer, as Gristwood suggests, that Robinson had an abortion— "Light o'love being notoriously 'a tune that goes without a burden', as a punning footnote explained" (Gristwood 2005, 204-5). The change of the narrative from miscarriage to abortion is a deliberate slur.

In 1799, the overworked Robinson became seriously ill. Although her physician did not expect her to last the night as she was "in extreme suffering and peril" (Brewer, 285), Robinson survived and enjoyed a short respite from her health problems, becoming the poetry editor for the *Morning Post* in February 1800. As poetry editor, Robinson became acquainted with Samuel Taylor Coleridge who took an interest in Robinson's health and suggested to William Godwin on 21 May, "Humphrey Davy has discovered a perfectly new Acid, by which he can restore the use of limbs to a person who has lost them for many years...in cases of supposed rheumatism. At all events, Davy says, it can do no harm, in Mrs Robinson's case—& and if she will try it, he will make up a little parcel, & write her a letter of instructions &c." (Gristwood 2005, 362)

Whether or not Robinson tried this cure is unknown and when towards the end of the year Robinson's health deteriorated, she was advised to go to Bristol to take the waters. As her annuity from the Prince had not been paid, however, Robinson could not afford the recommended visit. Robinson wrote to the Prince and appealed to him on the basis that she had been "pronounced by my physicians to be in rapid decline, I trust that your Lordship to assist me with a part of the sum for which you are indebted to me" (Brewer 2009-10, 288). The Prince, however, did not reply.

Soonafter, in a spirited letter to William Godwin she highlighted the effects of her illness both on her body and on her mind: "Had you been, in the spring of and bloom of Youth frost-nipped by sickness an consigned by premature old age; Hurled from the most flattering prospects of Delight and fortune to contemplate a long and dreary perspective which only the grave could terminate, would not your spirit, like my own, be weary of its Journey?" (Brewer 2009-10, 320) .

On 2 September, Robinson had an accident that caused her terrible problems and perhaps hastened her death. However, in a letter to Jane Porter on September 10, Robinson described it in humourous terms, writing: "[M]y coachman, probably mistaking me for a truss of Hay, in lifting me out of the slanting room where I slept, forgot the low roof, or rather penthouse, and threw me with considerable violence so high in his arms, that the top of my head absolutely cracked the ceiling. Had the adversary my brain encountered, been nearer of its own quality, (of *wood* or *of lead*,) I had never lived to write this letter" (Brewer 2009-10, 324).

The accident increased the frequency of the periods that confined Robinson to her bed, "every day expecting to prove that 'There is another, and a better world'" (ibid., 328). At this point Robinson was in great pain and her health was declining fast. Her friend John Walcott, also known as Peter Pinder, was a doctor and he stated that a "physician can do little more than watch nature, and, if he sees her inclined to go right, give her a shove in the back" (Gristwood 2005, 362). By December, Robinson was nearing the end of her life. The *Morning Post* of 13 December 1800 reported, "Mrs Robinson is very dangerously ill, and is attended twice a day by a physician". The *Continuation* tells that Robinson, dying of dropsy, had to be propped upon pillows because she feared that she would drown from the water on her chest. Robinson died on Boxing Day. Her body was autopsied and in addition to the dropsy, they found six gallstones which must have caused her immense suffering.

However, after a lifetime of criticism by the press, the obituary Robinson had received in the *Morning Post* read:

> The Literary world have to regret the loss of Mrs Robinson, who died on Friday morning at eight o'clock, at her cottage on Englefield Green. She had been for several months in a declining state of health, which worldly troubles greatly aggravated. In her last moments, however, she was consoled by the tender attention of her daughter and of many friends, who deeply lament that a woman of so much genius, of such elegant taste, of so

> rich an imagination in poetry, should be cut off at a period when the mental faculties are in their prime.[20]

Through her writing, Robinson achieved a level of respectability that she could not have expected in the 1780s. However, to achieve this level of respectability in order to negate the Perdita figure, Robinson had to "disperse her self-presentation across a number of genres and pseudonyms, to cultivate content-less, observational subject position, and to draw a firm distinction between the poet and the woman" (Mole 2009, 196). It is through these multiple authorial selves that Robinson was able to reinstate her reputation, at least in the literary world.

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Notes

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[1] William Gifford, *The Baviad: A Paraphrastic Imitation of the First Satire of Persius* **(**London: R. Faulder 1791), p. 23.

[2] *Gazetteer and Daily Newspape*r, Thursday 31 July 1783.

[3] *Morning Post*, 21 September 1782.

[4] In his work on Charles James Fox, L. G Mitchell quotes letters from Lady S. Lennox and J. Hare which discuss the affair and the press responded with a number of articles and caricatures.

[5] *Morning Post and Daily Advertiser*, 16 May 1783.

[6] *Morning Herald and Daily Advertiser*, 13 June 1783.

[7] There is no common consensus for the cause of Robinson's ill-health either by her critics or her modern biographers. However, Paula Byrne does offer a convincing case for acute Rheumatic Fever that was rife in eighteenth-century England and likely to be induced by a streptococcal infection caused by a miscarriage. According to Byrne acute rheumatic fever most commonly affects the joints and it also weakens the heart and Robinson died at a relatively young age of dropsy. There is also speculation by Hester Davenport that Robinson may have had Guillian-Barré Syndrome. However, despite the suggestion in some reports, Robinson did not immediately become completely paralysed. Although frail, Robinson was back in London society by the end of November—which roughly equates with the six-month illness reported in her *Memoirs*.

[8] *Morning Post*, 16 August 1784.

[9] *Rambler's Magazine*, December 1783.

[10] The full inscription reads: "memoirs of the fair one who fills the following sheets, has never been given to the public but by a piece-meal, and in detached morsels; while the following history may with propriety be said to be dictated *by herself*: many of the mere private transactions were indisputably furnished by her; nor could they possibly originate from any other source…Not that the editor insinuates any *particular* intimacy with the lady: he only assures the reader that, that the circumstances of her life were communicated by *one* who has for several years been her confident, and to whose pen she has been indebted for much newspaper panegyric. After this assertion, the public must place what degree of credit they please in the authenticity of these memoirs" (pp. iii-iv).

[11] *Morning Post*, July 1784.

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[12] *Rambler's Magazine*, August 1784, p. 281.
[13] *Rambler's Magazine*, August 1784, p. 281.
[14] *Rambler's Magazine*, August 1784, p. 281.
[15] *Rambler's Magazine*, August 1784, p. 281.
[16] *Rambler's Magazine*, August 1784, p.359.
[17] *The Morning Post*, 14 July 1786. The full quotation reads, "This Lady had she walked in the paths of virtue and peace, would have been an ornament to her sex, and a peculiar happiness to his of whom she was the *better half*. But a spirit of levity, and strong propensity to dissipation, and the *haut ton*, overcame her virtue and her sense and not guarded by the *sturdy oak*, but by learning on the *feeble bending twig* as a protector, she easily gave way to the flatteries, the follies and the vices of those who paid their court to her".
[18] *Rambler's Magazine*, August 1786, pp. 302-3.
[19] *Rambler's Magazine*, August 1786, pp. 302-3.
[20] *Morning Post*, 29 December 1800.

CHAPTER TEN

"OUT OF PLACE IN ETERNITY": DOING TIME IN THE POETRY OF FRANCES BELLERBY 1899-1975

KYM MARTINDALE

> Here, then, is executed the perfection of a design
> Brought from and through all Time
> Into this moment—into this timed moment
> Out of all Time past and all to come—
> Into this accurate timed moment which being perfect
> Could not be out of place
> In Eternity.
>
> —Frances Bellerby, "In Place"[1]

Absolute violence—absolute in the sense of the utter destruction of an individual by the direct hit of a shell—was at the heart of the poetics and philosophy of the poet Frances Bellerby. For Bellerby, only thirteen when her idolised brother Jack was killed, the moment of his death in 1916 was a severance that came to inform her poetry with a profoundly charged sense of rupture, but equally, an understanding of perfection: of design, of form, and of "wholeness". This perfection comes to be located emotionally in a past, which as it recedes, reveals continued existence to be increasingly flawed, and the past itself as another world from which Bellerby is banished. Imperfection of being was further emphasised for Bellerby by her own illnesses in adult life: as a child and a young adult, she was physically agile and delighted in her body's capacity for movement. The advent of spinal problems in her twenties, and later, breast cancer, represented a loss of physical form; this loss is mourned not only in the content of Bellerby's poems, but haunts their metre, their lineation, and shape. The paradox in Bellerby's case is that perfection of design is ultimately only to be found in *formlessness* of being.

This chapter examines two of Bellerby's poems, with reference to her other writing and archive material, in order to demonstrate how form mattered at a fundamental level to Bellerby's attempt to reconcile her own exile from perfection in life, with her brother's apparent achievement of it in death. Her poetics, I argue, are as expressive in their formal strategies as they are in their imagery or vision.

Bellerby's privileging of poetry, as *the* literary form par excellence is Arnoldian in its veneration, and its gift is spiritual. Having written in and revered the form as a girl, she wrote very little as an adult until she was alone, while living at Plash Mill near Bodmin, Cornwall; it is clear in her various accounts of her beginning to write poetry again, that poetry seems to have an external and mystical force, and that conditions must be propitious for its appearance. This recollection, in a letter dated 1970, is typical:

> I remember very clearly the Presence in the lamp-lit room, the tremendous, deep still excitement, the immediate writing down of dictated words. (Gittings: Stevenson 1986, 23)

The sense of the sacred is beautifully conjured up, while poetry itself is deified; the words come to Bellerby as if she were merely the conduit for a higher being. The experience as it is described, also believes unequivocally in the notion of the muse. To understand that poetry held this status for Bellerby is integral to how we read her use of poetic form, but there is a further point: she noted in correspondence with Charles Causley, how in her youth poetry "made sense", while athletics and other physical pursuits "made unity of body and spirit" (Charles Causley Papers, 1969). There is much riding on the verb "made" here, if it is understood not merely as grammatical function, but also for its allusion to crafting, shaping, or indeed, forming. It suggests a deep awareness of form as aspiration towards wholeness and perfection. Moreover, "made sense" accords both poetry and physical activity agency, as they "make" order and wholeness, repeatedly. In other words, both labour continuously in the cause of "form".

My overall argument is better understood if we turn first to the facts of Bellerby's life. The current edition of Bellerby's selected works, edited by Anne Stevenson (1986), has as its preface a biography by Robert Gittings. This remains the best summary to date, in prose, of Bellerby's life; I say "prose" partly in response to Sabine Coelsch-Foisner's argument (2002), that Bellerby, who struggled to write her autobiography, and never succeeded, offers her life nevertheless in her poetry. Coelsch-Foisner's reading is helpful to this essay since I argue that Bellerby's understanding and manipulation of poetic form are expressive of her frustration at what she perceived to be her own flawed body, which in turn stood in relief against the "perfection" of her brother's death. As Coelsch-Foisner argues, and I agree, Bellerby's anxiety concerning form and perfection of design confounded her attempts to write the autobiography since that mode could never achieve both factual and/or psychological truth *and* formal perfection (358-671 passim).

To return to the facts of Bellerby's life: as Gittings records, she was born in 1899 in Bristol to Reverend F. Talbot Parker and his wife Marion. Her upbringing was hostage to her father's missionary zeal where his calling was concerned, so that Frances and her brother Jack lived in poor areas of Bristol, somewhat isolated in their middle-class existence, but gaining an appreciation for the less material things in life. Gittings cites Bellerby's observation on her and her family's tendency to sacralise objects and people, in the sense that "everything was loved with a kind of sacramental ardour" (Gittings: Stevenson 1986, 10). Ironically, this isolation was later revisited on Bellerby, both in her marriage to economist John Bellerby, and on her separation from him. The couple were politically committed to living only on what they absolutely needed, and gave "surplus" earnings to those more needy than themselves, a decision which denied them the social milieu of both their own and other classes; when they finally separated, Bellerby lived alone in Cornwall, chiefly on Bodmin Moor, and in Kingsbridge, Devon until her death in 1975. She was isolated now by illness and pain, and dependent on friends and neighbours.

It was in June 1930, when Bellerby was in her late twenties that she sustained the tragic spinal injury that would dominate the rest of her life:

> [Bellerby] and her husband [were spending] a camping holiday on the Dorset cliffs at Lulworth, accompanied by another couple. Always exhilarated by the sea and swimming, she was running at full speed...when her husband tried to catch her. Handicapped by his missing arm [John Bellerby lost an arm in WWI] he failed to do so and she fell heavily on some rocks. (Gittings: Stevenson 1986, 17-18)

The damage made itself felt physically, but also psychologically with immediate effect: Bellerby later wrote of that moment, that she "felt at once that she was badly hurt" and that "I saw…tall golden letters: THIS IS FOR EVER" (ibid., 18). As Gittings continues, the "real pain started a month later", and the condition culminated in ankylosing spondylitis. This is a kind of arthritis of the spine, which results in a stiffening and fusion of the vertebrae. It is also, cruelly, a condition that more often than not begins in early adulthood. There is even now no cure, and the treatment currently seems to focus on management and alleviation of pain, stiffness and so on.

But in the 1930s, as Gittings notes, spinal treatment was even less hopeful, and crude. Bellerby found some relief in gentle swimming up until her early forties, but was increasingly immobile, and "caged" from within, by her spine. In notebooks and letters, she makes it very clear that her exile from her former physical agility and athleticism was deeply frustrating, but she also sees pain, especially chronic pain, as damaging in a much more fundamental way, to her concentration, to her mental abilities, and disabling in every sense. These excerpts from correspondence and archive material are expressive of her frustration, but also indicate a deep resistance to the notion of suffering as having any positive outcome. It is simply destructive:

> As for physical pain, I think there is nothing good to be said of it except perhaps of the acute kind which either comes to its own climax and end, or is ended. For lasting pain, pain that is always ready in waiting, what good can be claimed? It is ruinous, it is a millstone, it is cruel. I do not believe it to be the will of God. (Charles Causley Papers, 1969)

Gittings further cites the following, which again stresses Bellerby's refusal to accept pain but suggests too, how writing fails as catharsis:

> I HATE my spine. I am going to write this here because I want it out of me. I HATE my spine…I am NEVER used to it. I NEVER shall be…I NEVER shall be reconciled to *this*. (Gittings: Stevenson 1986, 19)

Finally, she writes to one of her long-term correspondents, Marjorie Battcock, in 1959 and as late as September 16, 1963, respectively:

> You are good to write to me as you do. I doubt whether you know how much it means to me that a few people really mind about the part of my "story" that I mind most: the damage to & hampering of my work. I find it quite intolerable, & have no philosophy which can deal with this. (Charles Causley Papers)

> Do you believe in "acceptance"? I don't. It's passive. I think one should "accept" what one judges to be "good" in origin or in potentiality. But otherwise one should determine to come to terms. A quite different thing. (ibid.)

Before I turn to the first of the poems under discussion, it is worth digressing on the matter of chronic pain, to explore how the personal material cited above goes directly to its uselessness and long-term effects. David B. Morris notes that "pain may be understood not only as a measure of intensity…but as a measure of time" and what he refers to as the "temporality of pain" is indicated in the etymology of the adjective "chronic" (Morris 1987, 152). Morris continues that the "contrast between acute and chronic pain" is a "temporal distinction" and "absolutely basic to modern medicine" (ibid.). This distinction is not without its problems, but Morris explains how, after six months or thereabouts, of "pain that is unresponsive and unremitting, a qualitative change seems to occur" in patients, who then police their expressions of pain before family and friends, and simulate some semblance of normality (ibid.). Bellerby's gratitude to Marjorie Battcock for understanding how she is "damaged" poetically and in morale by pain, and her longing to "want it out of me" echo Morris's observations: Bellerby cares profoundly that the hardship is not only the pain but that the invisible part of her story is the damage it does to her capacity to work, to write. One might say that it prevents her "being".

What further interests me in Morris's account is that chronic pain, while its measure is one of time (which is the essence too of narrative), nevertheless cannot participate or offer the theatricality and narrative of acute pain, since it "simply does not conform to the curative model" (Morris 1987, 153). Bellerby's comment that acute pain is only good for its coming to a climax or an end is a sharp acknowledgement of Morris's point. In other words, there is no pace, little drama and no resolution or happy ending. There is no ending at all. This denies form its function, the consolatory function of making sense, unity or wholeness, unless perhaps, form is itself wounded in some way.

Morris is writing in response to Elaine Scarry's seminal work *The Body in Pain: The Making and Unmaking of the World* (1985), which remains a benchmark for many in terms of philosophical enquiry into pain and self. He is critical of what he sees as Scarry's slighting of the "temporality of pain" but a more recent response to Scarry's work, by Martha Stoddard Holmes and Tod Chambers revises this (2005). Stoddard Holmes too, had thought Scarry overlooked chronic pain, only to re-visit the work and find her own reading to be wrong. One of Scarry's most exciting proposals, to literary and other scholars, was that pain eradicates language, and thus "self" in the sufferer, an argument Stoddard Holmes applied and taught in her own literature courses at California State University. When Stoddard Holmes was diagnosed with cancer, and underwent the usual gruelling treatment however, she filled a notebook with thoughts and feelings; her body became, she says, "a site not of language erosion but language generation" (Stoddard Holmes and Chambers 2005, 131). To this end, she develops Morris's observation concerning the disappointing potential of chronic pain as “narrative”, and makes the following distinction: acute pain, she claims, “makes for good theoretical discussion and good narrative, but, in the moment strains expression”; but chronic pain “presents a more challenging project both for theory and traditional narrative, to say nothing of patients and their physicians” (ibid.). For while it may lack “form” and drama, “[c]hronic pain’s very persistence over time permits a nuanced, linguistically rich study by both patients and doctors” (ibid.). She concludes that scholars and theorists misjudged Scarry’s text: “drawn to the keen lines of acute pain and the attractions of the unmaking of the world, we have bypassed the places in the text where the world is never quite unmade, but remade all the same” (ibid., 133). It is this quieter, but no less intriguing approach that is useful in considering Bellerby’s pain, and her poetic expressions of it; I include in this not only her physical or bodily pain, but the pain of bereavement. This latter, as we will see, also hurt her for the rest of her life.

I come now to the first poem, “That Risen Sun” given in full below.

That Risen Sun

Do you by chance remember
The sea suddenly puckering
As if to sneeze, or yawn?
And how we actually saw the slender wind, greenish silver,
Flowing out of the south-east towards which we started to
swim,
With the day in our faces? We could afford to let the gulls
Ha-ha,
Our darkness being over, our fears having proved flimsy as
shell.
Innocence and experience in our salt veins sang duet:
‘This risen sun shall never set’
(Bellerby: Stevenson 124)

A particular pleasure for Bellerby was swimming, as intimated above, not only for the physical and sensual delight it gave, but for the opportunity it afforded for reverie and spiritual possibility. In one short story, “Three Swimmers” for example, the protagonist Sheila is clearly modelled on Bellerby herself, when she experiences a Wordsworthian understanding of “everything” around her as she swims in a quiet river (Hooker: Bellerby 1986, 152). For Sheila, wild swimming achieves a state of transcendence. “That Risen Sun” recalls a similar moment, but the harmonious transcendence depicted in “Three Swimmers”, has become an occasion for grief. The grief is twofold, first lamenting the impossibility of the poet ever reaching that state again, while, second, the swimmers' innocence is mocked in hindsight as naivety. The transcendent moment is evident in the poet's certainty that "we actually *saw* the slender wind" (my italics), that the "darkness being over, our fears" are proven to be "flimsy as / shell" (Stevenson, ibid.). The dramatic irony of the speaker having held such belief is signalled by the past tense and the single quotation marks fence off the final line not only as song, but also as folly.

The poem exhibits a tautness and awareness of form in step with its content, from the brief first three lines, through the oddly long and complicated middle six lines, to the deliberately jarring closing couplet. This last seems to embrace and resolve the complexity of the ebb and flow of the fluid heart of the poem, the lines that are memory, water and air; yet, the march of the poem's first line quickly falls out of step as if to mimic the possible faltering that attends memory, recall, and finally, the "broken" body that must carry on. The penultimate line is suggestive of cusp in its momentary but definite pause, seeming in its stillness to offer stasis, yet presaging change. Each line is then aware of its "ending" as turn, which invokes the inevitable turns in the sea and wind.

These first three lines reward careful reading to appreciate their rhythm and measure (bold indicates where the emphasis falls):

> Do **you** | by **chance** | re**memb**er
> The **sea**,| **sud**denly | **puc**kering
> As **if |** to **sneeze**, | or **yawn**?

The first line begins with two feet of iambs but "finishes" with an amphibrach (x / x). The rhythm pushes forward as if the momentum and certainty of the iambs would carry us into the next line, and over the now stumbling amphibrach; thus, the rhythm keeps time with the enjambment, in both message and measure. We swing into the poem with some stride, like a swimmer braving the water, only to slow momentarily into the second line, again, like a swimmer encountering the swell as the water deepens. The second line returns to iamb with "[t]he **sea**", but shifts immediately to two feet of dactyl (/ x x | / x x) with "**sud**denly | **puc**kering". The hesitancy is again pronounced, and begins to impose a quite different rhythm, just as seas, sneezes and yawns do: they are all irresistible, yet hostage themselves to other forces. As such, the falling amphibrach, which is like a limping iamb, and the two dactyls give a very different complexion to the sudden and apparently confident return of the iambs in the third line: "As **if |** to **sneeze**, | or **yawn**?" The neatness and authority of their measure is put into question, not only by the ironic conditionality of “as if”, but by the broken pacing of the first two lines. All this readies us for the question mark itself, which concludes the third line, but demands the rising inflection that suspends the poem briefly.

The question continues in a wondering voice, across the centre of the poem, and these lines also stand out for their lineation. The marked alteration in length, the introduction of caesura, and the deliberate decision to indent one word mid-page in three of them, introduce a contemplative mood. The three lines that continue to a single word line are particularly compelling. In two instances, the hanging word is monosyllabic, falling like a gavel on the soft optimism of the long preceding line. In the other case, the onomatopoeic “Ha-ha” is in itself empty of meaning, literally sounding only laughter, which the swimmers can—they believe—allow. Yet, the imprudence of this response is again highlighted by “Ha-ha” occupying its own line, and hence it claims a new space in which to resonate. All three of these lines now seem to rest precariously, typographically and philosophically on one word, one note, and an incomplete metre, in which the swimmers’ hopes are swallowed.

Bellerby said of this poem that it “might be the happiest, and almost the unhappiest, of all my poems” (Charles Causley Papers). This captures much of what Bellerby was about, as the speaker and the poem return to a certainty that is ultimately illusory, despite being born out of “innocence and experience” and in harmony. But the work of form is integral to the sense of the poem, its feel and sound, its look on the page. The final couplet confirms the tragic irony of the position from which Bellerby now writes, the fluidity of the stanza now *falsely* and hopelessly caged in the stricter cadences of these lines, much as Bellerby was caged by her ankylosing spondylitis, and the remedial spinal jacket she wore at one point. If we examine the metre of the final lines, they too reveal the mechanics of their intention, for despite the lovely cadence and lilt of the penultimate line, there is a strange syncopation on the word “and”; and the last line when read out, is brutal in its truncated scansion.

> **Inn**ocence | and | ex**per**ience in our **salt** veins sang **du**et:
> ‘This risen sun shall never set.’

I have not scored the closing line, as I wish to focus on the way in which the monosyllabic words function against the line’s apparent message. Hope and assurance are initially fenced off in quotation marks; this strategy, while it indicates a quotation, and establishes the line as the swimmers’ song, nevertheless puts the content of the words more deeply into crisis. The monosyllabics of “This…sun…shall…set” march firmly to the beat, but “risen” breaks in awkwardly, bumping into “sun”; the ostensible promise of endless sun is now undermined by the halted measure, the stress thus announcing that, after all, "this sun shall set". The other duo-syllabic word, "never" ironically regains the rhythm, but is now perhaps wedded to its negative aspect, falling with a thump on "set". Finally, the line seems amputated in contrast to the expectation created by its predecessor, and the rhyme arrived at prematurely, mimicking the abrupt and premature infirmities suffered by Bellerby.

In other words, the poem closes on a line from which *something* has been taken. Its form, importantly, is still bounded by the rhyme, but the foreshortened metre calls attention to, and sounds aloud, this "de-formity" of measure. This is what I mean by form that is wounded in some way, working towards "making" sense. It articulates a world in the process of constant remaking, while the wound gapes at the end of the final line.

If this poem deploys "broken" form to suggest the deforming aspects of pain, and pain therefore as imperfection, the next poem addresses the idea that death achieves perfection of form in formlessness. Its irony is that as a poem, it relies utterly on form to communicate this, and it is unsurprising that the final stanza focuses on trusting new "forms".

A Clear Shell

The fire burned my body to a clear shell.
Though whether the fanning tempest blew from hell
Or heaven I could not, cannot, tell—
Who have no sense
Left for so nice a difference.

But I learned the essential function of extreme pain—
Of liquid fire pouring again and again
And again through the horrified body: such pain
Makes wholly innocent
Therefore am I impenitent

Today. Today ask no forgiveness,
Having nothing to be forgiven. And my soul, no less
House-proud than at the beginning, shows Death
Smiling over the place,
Trusting this new face.

(Bellerby: Stevenson 98)

The poem echoes Bellerby's short story "The Green Cupboard", where the narrator muses how her uncle, Paul, "blown to pieces" (just like Jack) meets an end which perfectly fits his life. "Paul as a corpse" the narrator observes, “would indeed have been ludicrously incongruous” (Hooker: Bellerby 1986, 125). The story reads as a manifesto to some extent, for Bellerby’s understanding of form as essential to order and truth, harnessed here to a notion of destiny; in the end, it comes down to perfect design:

> [Paul’s death was] inevitable, and perfectly fitting. A man’s death is born with him, and grows to fulfilment as his life grows. In a sense it is our lives that develop our deaths…Paul’s death as a soldier grew in him apace from the very start of his brief and most flourishing life. The very manner of that death was, obviously, inherent in his life. He was blown to pieces at dawn one summer’s morning. Nothing to bury save of the most anonymous and meaningless description…No fuss, no fume, no corpse. (ibid.)

Returning momentarily to the distinction between acute and chronic pain, can there be any pain more acute than that which utterly annihilates body, and ergo self? It is acute in that it happens with totality. By its very nature then, it cannot be repeated or protracted, since in its aftermath nothing remains. That is its beauty and perfection: there is nothing to corrupt, this body is beyond time. In the case of Paul, only words are left, which since they are “anonymous and meaningless” cannot harm or mark “Paul”.

Yet the poem complicates the clarity of Paul’s (or Jack’s) case, with several significant differences. Most obviously, the annihilated self speaks; second, the same “self” experiences the “liquid fire” and “extreme pain” over and over again, that it may, third, learn “its essential function”; last, this “self” understands its status as post-mortem. The repeated pain is not chronic, and I state this with confidence for two reasons: the poem places the whole experience in the past tense, and Bellerby, as noted above, saw no good in pain unless it was acute, came to its own climax, and ended. This pain seems to succeed in that respect, to remake world and self, but again out of time’s reach. This pain has narrative, and thus defers to form.

It is as if in the poem we hear Paul, or Jack, from beyond the grave. However, the speaker demonstrates an ontological security: the lineation of “my soul, no less / House-proud” insists that the self is not diminished, since it is “no less”, while the phrase “wholly innocent” gestures simultaneously towards wholeness and the sacred (I will return to the phrase “wholly innocent” below); then too, this “I” is also “impenitent”, so certain of self that it does not seek absolution. It even trusts in Death.

Death’s place in this logic of perfection is at first surprising, for, despite deeply held religious beliefs, nowhere does Bellerby alleviate her loss of Jack by envisaging a reunion post-mortem. Rather, like the narrator of “The Green Cupboard” she enshrines Jack’s demise as the fatal promise of everything he was when he lived. Its manner completes the flawless design of his life leaving "no mess, no corpse" hostage to the continuing ravages of time: perfect form is formlessness, and the paradox of Jack is that his literal formlessness in death "forms" the perfection of his life. In this view then, death is a resolution. It is also the reverse of "making", as Bellerby inverts Diotema's idea of poetry as that which, in Susan Stewart's words "is the creation of being from non-being, the emergence of form out of nothingness" (2002, 327).[2]

And yet, there is a making of sorts. The poem pivots on the pun of "shell": it recalls the armament which obliterated Jack's body, but also the hollowed, then harrowed and finally hallowed and absent body itself; for this reason it is important that "shell" closes the first line, then determines the rhyme for the better part of this stanza. A further pun in "wholly innocent" also invokes "holy", "hollow" and "hallow", yet it is as a consequence of *knowing* herself to be "wholly innocent" —an oxymoron— that the speaker can state unequivocally that she is "impenitent". The pain is "liquid fire" and clearly purging, which suggests that it is infernal or purgatorial, yet the provenance of the "fanning tempest" that inspires it, is a matter of indifference to the speaker, who has "no sense/Left for so nice a difference". This pain comes close to undoing the self in Scarry's understanding of it, but Bellerby veers away from total undoing: as the "horrified body" is cleansed, in an almost phoenix-like regeneration, it has earned its own state of grace. "I" is re-made in its acknowledgement of that pain, and out of the harrowing it enforces.

This is not a self martyred, or proven through suffering, however. There is a scepticism colouring the poem, which suggests "I" believes in some sort of agency and/or secular imperative. In the first place, the pain, as noted above, is neither heaven-sent, nor diabolical; "I" we recall, is certain that one is indistinguishable from the other, and moreover does not care. Then too, the innocence that is apparently its consequence is undermined by the speaker's *stating* she is "impenitent" with the authority of reason implicit in "therefore". This wilfulness continues as "I" insists she has "nothing to be forgiven", and her "soul, no less/House-proud than at the beginning, shows Death/Smilingly over the place/Trusting this new face".

The poem's taut syntax, the turns in the rhythm and rhymes of each stanza, Donne-like in the use of wit and form, are brought into the service of the argument. For example, the last two lines of the first stanza, "Who have no sense/Left for so nice a difference", send us back to reposition "I", to ascertain precisely who is "Who"? This is so swiftly done that we only just notice or feel the break, but if we do not notice it, we lose the poem's direction; Bellerby makes the reader almost practice to get the rhythm correct, as one might a piece of music, and thus pushes a re-engagement with the lyric "I". The dash at the end of line 3, lies on its side like the faint ghost of "I", only to be resurrected through the force of voice alone: for this "I" is also senseless—"I […]/Who have no sense". In that enjambment, we have the contradiction of a self announcing its own formlessness.

Bellerby was repeatedly compelled by Death's promise and yet insistent that it had no dominion. Gittings argues that Bellerby's poetry more often expresses acceptance or resignation (Gittings: Stevenson, 40), in contrast to the agony found in the notebooks and letters, but I disagree. Her expression in her private writing is forthright because it can be. It has no need to be "poetic", and this is where it is important to recall the reverence Bellerby held for poetry. The voice in her private letters is simply hers, but poetry for Bellerby comes from elsewhere, and she merely "listens". Thus, her poetic "I" is complex and layered in its attempts to "make sense" where the "I" of her correspondence or notes seeks only to communicate. The poetry is caught in an ambivalence towards her physical suffering, which in turn indicates a struggle concerning its place in her life. Bellerby needed I think, to have a reason for the pain, loss and illness she endured, but could find none, and for someone so implicated in belief or faith, this itself must have been a kind of agony. "A Clear Shell" is an enigma: it rests on a spiritual dilemma in that death is preferred to pain; the self also goes defiantly and trustingly towards death, insisting that it has attained grace—through pain. The poem is formed out of an intensely acute agony whose "essential function" is in fact to provide, in Bellerby's words, "its own climax and end" (Bellerby: Stevenson 98; Charles Causley Papers). The final lines of this poem rhyme and scan with a smoothness that reconcile the poem's battle as that is evident in the twists, caesurae and enjambments of the previous stanzas. The first stanza's closing lines rhyme but fail to scan, and as noted above, syntactically force the reader back to the third line for meaning; the second stanza offers final lines which break the rhythm as the last line begins a new sentence which leaps startlingly into the third stanza: "Therefore am I impenitent/ / Today". The poem's closing couplet however, with its opening dactyls and anapests, offers cadences that intone a gentle falling into line, while the rhymes are certain and stand unassailably together:

> **Smi**lingly | **o**ver the | **place**,
> **Tru**sting | **this** new | **face**.

Susan Stewart observes that "the fate of pain" is "the finality of aesthetic form; but, even given this finality, aesthetic form constantly is put under pressure to change and renew itself in order to accommodate what time and experience have brought to it" (Stewart 2002, 328). In this sense, Bellerby's poetry, as these two examples show, bends form to her experience, and to her time. But "That Risen Sun" is the less happy of the two poems: it concludes with the speaker not resigned as such, but unable to see beyond the inevitability of the sunset and the end of light. The subject emerges as "the figure of poetic making" (ibid., 329) but imprisoned, and far from formless, held by and in "*de*-formity". In "A Clear Shell" however, Bellerby articulates Stewart's paradox, just as Stewart here, explains Bellerby's:

> By means of the incantatory, the poet acknowledges in the [poem's] very being this inevitable paradox of human life: that we actively pursue an *eidos* or fixed image of the human and at the same time passively long for its dissolution. We dream of returning to the sphere of elements from which we have come—even if this means we must imagine ourselves as a kind of thing. Every glimpse of our mortality presses us toward creating some adequate mark in the face of our disappearance. Yet this very aspiration for an immortality of form at the same time is mastered by a demand for the form's erosion…The incantatory—that poetry created in a state of possession, and therefore by means of a wilfulness beyond the will of the speaker, that poetry of compulsive rhythms known not only through the body but through the memory as well—is…not a mere disfigurement of a stable representation. Rather, it provides the most full or "true" account of the fleetingness of the human countenance and the complexity of the human figure subject to time and suffering. (ibid.)

The notion of the incantatory, of poetry written in a state of possession, is one that Bellerby might recognise, in her lamp-lit room with the Presence dictating poems to her. She would also recognise the irony of the desire for immortality of form that simultaneously demands its erosion. She may map the sphere of elements differently, she may not long *passively* for dissolution, but she thoroughly understands the relationship between artistic form and truth of human experience. That is the paradox of Bellerby's reckoning with pain, loss, and the always just-withheld promise of perfection of form with which poetry consoles, seduces and torments us.

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[1] I would like to thank David Higham Associates for their kind permission to cite from Bellerby's unpublished letters and mss; all these are held at the University of Exeter Special Collections, on their Streatham Campus, as part of the Charles Causley Papers. I would also like to thank the archivists there: Dr Christine Faunch, and Dr Jessica Gardner (now Director of Library Services at University of Bristol) for their unstinting help and enthusiasm. Finally, many thanks also to Bellerby's loyal publishers, Enitharmon Press for their support and generosity in allowing me to cite from Bellerby's published work, and for their continued interest in Bellerby herself. Both the poems cited here in full, and further extracts from Bellerby's published work are reprinted here with their kind permission.

[2] Diotema figures in Plato's *Symposium* as one who argues for poetry as a form of self-creativity that has both spiritual and moral force.

CHAPTER ELEVEN

"FREEZE FRAME": WELL-BEING, PARALYSIS AND DYING IN THREE CONTEMPORARY TEXTS

HELEN THOMAS

This chapter examines the autobiographical works of Laurie Clements Lambeth, Robert Murphy, and Jean-Dominique Bauby in the context of critical and chronic illness, paralysis and imposed immobility. It highlights the ways in which these texts (in their poetical, diarized and critical forms) explore the experience of illness in relation to lack of agency, physical "imprisonment" and contemporary attitudes towards dying and death. The texts discussed here are seen as powerful narratives of subjectivity in their efforts to articulate "life" and "well-being" in the context of illness and death, and at times, to provide meaning and testimony whilst also examining the limits of medical practice and critiquing the legal discourse concerning rights. These first-person narratives of illness and paralysis not only demonstrate the ways in which autopathography "offers a subjective complement to the objectifying rhetoric of the medical history" in order to assert the "phenomenological, the subjective, and the experiential side of illness" (Hawkins 1993,12), they also resist Foucault's metaphor of "docile bodies". Many offer searching accounts of the experience of the "failing body", the interruption of interpersonal relations, including the erotic and/or sensual desires, and the denial/censorship of rights in the context of illness, paralysis and death wishes including assisted suicide/euthanasia. In their poignant accounts of hypervigilance, pain, and loneliness, these texts forcefully prompt us to reexamine our understandings of *vitality*, "existence", and what it is to be human.

As the title of this chapter—*freeze frame*—intimates the concept of the "still" body appears at odds with definitions of life and mobility—life redefined as "still life". Paralysis suggests at once, a vivid, yet motionless body, *frozen* in time and space. Moreover, as intended by the Greek origin of the word, "paralysis" signifies "loss" in several ways. These narratives of physical immobility, sudden paralysis and locked in syndrome articulate not just failures of the body such as loss of predictability and crises of control, but other "losses" and concerns relating to subjectivity and agency—problems that require new and more self-conscious solutions to experiences of pain, trauma, and the liminal spaces to which these authors are subjected. Indeed, in *The Wounded Storyteller* (1995), Arthur Frank makes the pertinent comment that during illness, people who have always *been* bodies "have distinct problems *continuing* to be bodies, particularly…the same sorts of bodies they have been" (Frank 2013, 318). In their articulation of loss and paralysis, these accounts extend and revise the captivity genre via their articulations of imprisonment, heightened self-consciousness, and desires for freedom/liberation, whilst delineating new tropes of "economies of physical entropy, and concepts of 'being'". In many ways, these autopathographical narratives concur with George Bataille's idea of "disintoxication", reminding us of mortality and the definitions of living and being. These first-person narratives act as testimonies—as witnesses of unique experiences that have often been silenced or considered "taboo", "contagious" or corrupt—and as powerful efforts to communicate with others. They also offer a language to "speak the unspeakable"—either in terms of the loneliness and pain they reveal, the medical, social, gendered and/or legal critiques they utter, or indeed, their attitudes towards euthanasia or assisted death (Frank 2011, 182). For these authors, the experience of sudden paralysis, medical trauma and/or chronic pain instigates an "abrupt descent" into "a dark, dark place"—a hellish world of incomprehension and terror that corresponds with the literary gothic or sublime. "How do you put hell on paper?" asks Heshusius, for chronic pain which has "no external referent" and collapses modes of communication? (Heshusius 2009, xxiii). "While doctors can see heart disease, cancer…they cannot see pain"— it is instead a "silent epidemic". Chronic pain, like the consequences of medical trauma, "constitutes a radical assault on language and on human communication" (Morris 1993, 9). Moreover, these autopathographies also reconfigure the un-representable nature of illness and disease as a sublime power, or "deafening silence", that prohibits/limits communication, yet amidst which the narrator strives to make him/herself heard.

At the centre of these texts is the individual who is "subjected" to disease, isolation, medical discourse. Yet, as these narratives reveal, that subjectivity is seen to metamorphosise, be transformed under the influence of external factors, internal reflection and varying opportunities for patient agency. Thus, illness transforms the individual into someone/something else. It resituates the individual on the boundaries between the human and the "object"/thing that is perceived; the marginal space between the living and the dead. As these texts explore and question that marginal space, they reinvigorate questions concerning what it is to be alive, and what is it to "have a life". Furthermore, these texts interrogate concepts and practices of "well-being" in both the context of paralysis and critical illness, as well as the divergent, but sometimes overlapping, philosophies of hedonic and eudaimonic "well-being". Whilst the hedonistic version denotes Aritippus' idea of pleasure-based happiness, the eudaimonic reading, defined by Aristotle, prescribes a sense of self-fulfilment and satisfaction. Both philosophies, however, highlight the importance of place and social community for the individual (Atkinson 2012, 2).

Pain and Paralysis

Paralysis usually suggests a bodily frame suspended or *frozen in* time and space, whilst "pain" suggests a body *in agony*; wherein stillness and "peace" are denied. The writings discussed here highlight the experience of both pain and paralysis for their authors, as well as their increasing influence. As Frank and others contend, the ability to "*represent pain*" is problematic. Pain itself appears to be inexpressible: "Pain is the black hole in which language seems to disappear" (Frank 2011, 182, 184). Pain is seen as a "sign", a symbol of "dis-ease", "an unpleasant sensory and emotional experience"—yet one which appears to defy representation and narration. Whilst the Victorian physician, Dr Peter Mere Latham, capitalized the term "Pain", thus highlighting its authenticity and its status as an object, philosophers such as Wittgenstein situated pain as an "event" and function of "social interaction" (Bourke 2012). The problem of pain's "inexpressibility" and its frequent persistence in cases of chronic/critical illness highlights our dependence upon language as well as our yearning for symbolism, modes of interpretation and frameworks of meaning.

The experience of illness and paralysis has the effect of increasing the complexities involved in determining firstly, *what* the body *is*—"The body is a material organism, but also a metaphor" (Turner 2008, 6)— and secondly, what the *self* constitutes and the value of life "itself". Maurice Merleau-Ponty redefined the "body" as no longer "an object of the world" but as "our means of communication with it", thus "fashioning our experience and thought" (Merleau-Ponty 2002). However, the texts discussed here reveal situations where the body "malfunctions", dependency upon medication becomes acute and communication with the world is severely reduced (Merleau-Ponty 2002). Experience, social relations, and even thought itself become radically transformed. For some narrators, existence becomes predominantly imaginary, almost virtual. The symbolic and imaginary realms of Lacanian thought involuntarily replace the realm of the "real" (Robbins 2005, 194), whilst the "virtual" of Baudrillard's vision takes on the menacing spectre of the everyday. Individual agency and subjectivity appear imprisoned/bereft, existing entirely upon the "surface" in a sinister reworking of Jameson's reading of simulacra and postmodern culture (Frank 2001, 192; Jameson 1991, 9). This chapter thus considers the ways in which these autobiographies represent and manage narratives of immobility and paralysis, engage with concepts of defeat, victory or survival, articulate periods of reflection or reassessment and revise notions of "well-being". In their efforts to integrate with established representations of subjectivity they present sophisticated engagements with sociopolitical relations (including race, gender and sex) and established literary genres and make observations about malady and mortality in contemporary culture.

Death in Contemporary Culture

> At the core of the "rationality" of our culture…is an exclusion that precedes every other, more radical than the exclusion of madmen, children or inferior races, an exclusion preceding all these and serving as their model: the exclusion of the dead and of death. (Jean Baudrillard 1993, 126)

According to data from the Dying Matters Coalition, set up by the NCPC (National Council for Palliative Care) in 2009:

> "Only 35% of us [in the UK] have made a will, yet 70% say they are comfortable discussing death"
> "Only one in nine of us have made our funeral wishes known to our families and friends"
> "Instead of accepting death as natural, medicine makes us think something can always be done to stave it off"
> "Multiculturalism means we're surrounded by examples of ritualised grief from other cultures".

Many practitioners and researchers see death as a social construction—as an event or phenomenon powerfully "embedded within, shaped by and constructed in concrete historical, social and cultural contexts" (Jacobsen 2013, 13). During the last three decades, research by thanatologists, professionals and academics with backgrounds in sociology, anthropology, and religious studies has highlighted the persistence of traditional trends, as well as recent changes in relation to illness, death, dying, bereavement and care. These include the practice and ethics of end-of-life care, the subjective treatment of illness and death (Carel 2008); care for the elderly, weak and ill; end-of-life decisions; "death education"; varying rates of organ transplantation (Markussen 2013) and attitudes towards suicide and euthanasia.

Whilst recent medical, technological and social interventions have increased our average life expectancy (Brown 2008), many of us refuse "to live with death" or to accept its inevitability (Jacobsen 2013). However, in line with Philippe Ariès' insistence in 1974 that the era of "death denial" and taboo had passed—"death is once again something one can talk about" (Ariès 1974; 103)—philosophers, historians, sociologists and medical practitioners have noted the influence of the "death awareness movement" (Graven, Jacobsen and Lund 2013, 27-54); changing forms of mourning, funeral practices and memorialisation (Walter 1994); cultural and legal attitudes towards pain, illness, care, treatment, sedation, euthanasia and death; "social death" for those who die alone or lonely; as well as concepts of "good death" and "bad death".

Despite the impact of the "death awareness movement" in the UK during the 1950s as part of the modern hospice movement (via the work of Dame Cicely Saunders) and fatal-illness-specific movements and patients' rights movements in the 1960s, such as cancer and AIDS alliances (Brown and Zavestoski 2004; Allsop, Jones and Baggot 2004; Hess 2004), critics and historians have highlighted what they term the "disappearance" of death in the modern age i.e. its hidden/banned aspect from the public sphere when death took place in hospitals and care homes: "Death became disembedded from the local community" (Giddens 1990). Thus death in contemporary society is characterised by silence, privacy and an institutional setting, death "guided by the individual", even though, as Jacobsen notes, the objectives of the death awareness movement were to: acknowledge and re-inscribe death in society's activities and within the community; secure quality of life for the dying person in relation to pain relief, social, psychological and spiritual support; incorporate death in macro-social discussions (e.g. legal, ethical and practice-related) and "establish improved institutional settings for death and improved rights for people towards the end of their life" (Jacobsen 2013, 31).

Laurie Clements Lambeth, *Veil and Burn*

Laurie Clements Lambeth's poetry highlights the "feeling of true slowness", caused by her multiple sclerosis. Discovered in 1868 by the Parisian "father of neurology", Jean-Martin Charcot, Multiple Sclerosis (M.S.) is a neurological condition of the central nervous system that causes paralysis, numbness, walking difficulties and vision loss and is more common in women than men. As the disease manifests primarily by disorders in mobility, in 1887, the English photographer, Eadweard Muybridge, created a photographic study of the locomotion of a female M.S. patient with walking difficulties.

Fig. 11-1 Eadweard Muybridge, Photograph, 1887.
Female M.S. Patient with Walking Difficulties

M.S. is primarily caused by the immune system mistaking myelin, a substance protecting the nerve fibres in the central nervous system, for a foreign body and thereby disrupting messages between the brain and the rest of the body, causing them to slow down, become distorted and sometimes blocked completely.[1] The loss of myelin can also be accompanied by damage to the actual nerve system that can increase disability over time. As the symptoms of the condition depend upon which part of the nervous system is affected there can be many different symptoms of multiple sclerosis. Physical symptoms of multiple sclerosis can include problems with vision, balance, fatigue, stiffness, spasms and problems with speech—but it can also affect memory and thinking, and have an impact on emotions and instigate anxiety, stress and depression. This is partly due to the effects of the disease—but also, as Barbara Webster (who began to experience symptoms of M.S. when she was twenty-three) suggests, partly in response to the reception of the disease's symptoms *by* others. In *All of a Piece*: *A Life with Multiple Sclerosis*, Webster explains that whilst she felt that there was something seriously wrong with her body, she was told that her symptoms were a result of depression and her refusal to admit that her physical symptoms had a psychological cause was determined as a "pathological sign" (Webster 1989, 8). Webster's experience of the disease had a profound effect upon her "entire image" of herself and her integrity:

> I felt less whole…My whole notion of who I was threatened…My disability….At the best of times…was entirely invisible to others; at the worst of times, it was very visible as I stumbled along…My arm and leg were not the way they "should" be and…I was not the way I had once been. And this sense of disability with its accompanying feeling of no longer being in control flowed over into all areas of my life. My image of myself had been altered. (Webster 1989, 47)

Webster also analysed her experience of the disease "beyond the self", i.e. the impact of culture upon her experience, including attitudes towards chronic illness and the ambiguous character of M.S.:

> Disease is seen as having two outcomes—recovery or death. Disability is seen as being relatively stable and changing only for the worse…There is no slot into which I fit and that presents difficulties for me and others. My status is not fixed. MS…has disabled me but that disability is ever-changing and, moreover, is not always reflected in my appearance. (Webster 1989, 114)

In her poetical collection, *Veil and Burn* (2008), Lambeth describes the intensification of bodily experience caused by both the disruption to her nervous system—the left side of her body became numb at the age of seventeen—as well as her feelings of fear and crisis. Like the faded silk organza dress that has slightly faded with time, "oxidized and burned in the shop window" in "Coming Down", her body is also slightly flawed, "stippled with lesions" and her physical movements become heavy as she "hoist[s] the right leg / out of its silk encasement" and waits "a moment for balance" (Lambeth 2008, 1-2). In "Symptoms", Lambeth signals the condition's "predeliction for females" (almost three times as many women as men are sufferers of M.S.) and compares the oppressive and restrictive experience of the condition with the discomfort her grandmother experienced when forced to wear her "tight-laced corset" (ibid., 3). Lambeth's girdle, however, "seldom slips from her ribcage"; release comes only in the form of temporary remission followed by relapse. Although she is advised to rest as a cure, she becomes dizzy and unstable, and her body temporarily "ossifies" in mid-action: "Fix my mouth in a loose pout when speech / eludes its muscles, tired, stiff as the garments that hold me". The numbness that she experiences transforms her experience of her body into something held together by "cellophane wrapping my limbs" (ibid.) whilst the prose-poem, "Fragment Behind the Eyelid", describes the torturous pain of optic neuritis as it digs behind her eye, prohibits movement as it "grates" and releases a "constellation of tiny cobalt lights" (ibid., 8). In "Dressage, or the Attempt at Training the

Course of Illness”, Lambeth agonizingly describes the numbness that migrates, along the slowest route, “from left foot to…ribcage” and “presses in”. As the disease “takes as it pleases”, it “strip[s] away sensation” from her body, leaving in its place, a “space where nothing touches at all”. The touch of her lover’s hands, the “feel” of someone else’s skin is “there, but not there”. As the “invisible colonists” of M.S. invade her body, make a “home in her neurons” and “tear at her myelin”, she is “invited” to make metaphors of the disease, but she is “sick of it”: “This is when I pull the reins” (60-61).

However, as multiple sclerosis increasingly limits her mobility and vision, her poetry celebrates a different type of freedom of her body that she no longer enjoys. In “Riches” these cobalt lights become transformed into the “string of blue beads” at her feet, the dazzling L.E.D. lights in the club that halo “motion”, revere only “motion”, “only movement”: “Praise to all flinging bodies—this music, our buoy contains us” (9-10). In “Seizure, or Seduction of Persephone”, poetic form and content coincide to signify both the “broken”/split body and the ellipses/fragmented nature of language used to represent “caesura” or gaps between voluntary and involuntary movement, experience and representation. As the poetic narrator convulses, she watches:

> Both inside and   outside as her limbs
> flail ... and seize…   in the bed
> and speak in unknown tongues. (13)

In its reference to her “unruly body” (Graham 1997, 70-71; Hawkins 1993, 12), Lambeth suggests both the involuntary muscle spasms experienced by many M.S. sufferers, as well as the involuntary physical (orgasmic?) responses suggested by the reference to Persephone, the daughter of Zeus (the god of gods) and Demeter (the goddess of the harvest) in Greek mythology. Abducted and raped by Hades, the god-king of the underworld, who burst through a cleft in the earth, Persephone became the queen of the underworld, until she was released by order of Zeus. However, as she had tasted the food of the underworld (the seeds of the pomegranate), Persephone was obliged to spend half of the year on the earth (spring/summer) and the other half in the underworld (autumn/winter). Although Lambeth transforms Persephone’s rape/abduction to “seduction”, the emphasis upon physical action “against her will” is not lost in this translation. Moreover, the polarized aspect—between living and dying / summer and winter—is maintained by the growth and life that occurs when Persephone returns to the earth to be with her mother—

> [I] broke the earth,
> erupted and   pushed out
> a narcissus   by the roots

and the numbness and emptiness— "Some voidhere between my hips" that continues to link her to the dead, to Hades and the underworld (Lambeth 2008, 13-14).

"Large Loop Excision of the Temporal Zone" highlights the dichotomy between medical and sexual discourse in its revision of the procedure, a treatment that involves heating a thin wire loop in order to cut out the area of the cervix containing abnormal cervical cells. Although not directly connected with the immobility or paralysis caused by M.S., this poem suggests some of the tensions between medical and sexual identity, as well as the "gendered" aspect of the disease. Dedicated to Georgia O'Keeffe, the "mother" of American Modernism who created large-format, "magnified" paintings of blossoms, the poem makes a comparison between the medical gaze—the image of her cervix displayed on the video screen in the clinic in "extreme close-up"—and the view of lovers and female friends who "see" her emotional, sexual and creative identity foremost:

> Pale red and smooth, a little mouth inside.
> Flower. Red Amaryllis, each fold
> Deep crimson at center. (16)

As the fluid is injected into her cervix, it "transforms, turns blue as sky through bones in the desert" in order to illuminate abnormalities to be "excised" by the "hum of electric charge":

> Georgia, you'd understand—presence in loss,
> What is taken: what was saved. What remains. (18)

It is in the prose poem [*Gauze Fragment*], that the metaphor for the whole collection, *Veil and Burn*, and its links with bodily and visual paralysis, becomes clear. We are told that during Hollywood's golden age, a veil of thin material was used to "dissolve any harsh features or wrinkles in close-ups" and that cameramen burned cigarette holes into the fabric in order to "bring eyes to sparkle" (Lambeth, 39). The effect of M.S. upon the poet's vision "is something between the veil and the burn", or alternates between the two. Here vision registers both the sense of sight and philosophical understanding as suggested by philosophers such as Plato and W.E.B. Dubois, in his book, *The Souls of Black Folk* of 1903. In this text, Dubois' metaphor of the veil was used to highlight the veil worn by all African

Americans in racially segregated America as their view of the world and their access to potential economic, political and social opportunities differed so starkly from those of white people: “Then it dawned upon me with a certain suddenness that I was different from the others; or like, mayhap, in heart and life and longing, but shut out from their world by a vast veil” (Du Bois 1903). Yet the veil also instigated what Du Bois termed the gift of second sight, this determining the veil as both a blessing and a curse. For Lambeth, too, M.S. is a blessing and a curse—obstructing her vision, her “feeling” of her own body, and her relationships with others, yet allowing “her eyes to sparkle” as she sees the body and celebrates its movements and its sufferings more intensely in the same way that photographers create images that “arrest” the body, bringing it definition and clarity.

The Body Silent

In his autopathography, *The Body Silent* (1987), Robert Murphy, a Professor of Anthropology at Columbia University, noted that his own experience of “sudden traumatic damage” was followed by a period of “mourning”, a phase “precipitated by a profound sense of loss and…accompanied by the onset of melancholia” (Murphy 2001, 53). Paralysis for Murphy constituted a “progressive and total destruction” of his body, a “reduction of all volition to quietude” and an “entombment” of his mind “in inert protoplasm” (Murphy 2001, 29).

In 1972, aged forty-eight, Murphy began experiencing spasms and four years later, in 1976, he was told that he had a tumour on his spinal cord. This tumour progressed slowly into quadriplegia. Although primarily an autobiographical text, Murphy’s *The Body Silent* is also a critical study of illness and disability in contemporary culture—one which refers to the individual’s experience of illness in the context of cultural and literary references such as Hollywood, Freud, the Vietnam War, Franz Kafka and Samuel Beckett. Indeed, Felice Aull suggests that Murphy’s narrative is a form of “metapathography”, a term proposed by literary critic, Peter Graham to suggest not “simple” personal stories of illness but “artful transformations of the genre, works whose authors, relying on the distinctive professional strengths at their disposal” look beyond their own illness and suffering and look “past pathography itself” (Graham 1997, 73). Thus, Murphy’s narrative examines the social relations between the paralysed self and others, including work colleagues and friends. In particular, he comments on the altered dynamics of sociopolitical power and communication. Whereas previously he was “invisible” to the black policemen on the university campus, now they "know who I am and say hello". Murphy's text also reveals his anxieties about his changed relationship with his wife whose role as partner and lover has become that of carer. Communication between them is altered/stifled, leaving him to "guess" her emotions and concerns, and rely more heavily upon non-spoken forms of contact:

> We are held in thrall by my condition—we are each other's captives… Independence, self-reliance and personal autonomy are central values in American culture…Power relations between husbands and wives in modern society are changeable and problematic…Do I detect a note of impatience? Is she annoyed? Is she overtired? Should I have asked her? Does that slight inflection say, "What in hell does he want from me now?" This is not completely a concoction of my imagination, for we have been married so long we are thoroughly familiar with each other's rich subverbal vocabulary of tone, accent, stress, gesture, and facial expression. After all, we had learned in the Amazon to communicate in part-sentences, half-words, and grunts. In my disabled mindset, however, I pick up the right cues but I alter and magnify them, interpreting a small note of fatigue as major resentment and reading rejection into a fleeting expression of annoyance. The anticipation of such responses, in turn, affects the way I phrase requests…[T]here is a heightened self-awareness and guardedness in our relations that wasn't there before, and that has reduced openness and spontaneity. Our very attempts to avoid conflict through increased tact and delicacy have become part of the problem, not its solution. (Murphy 2002001, 199-214)

Murphy's diagnosis leads to a series of intense surgical operations, and at first, his response is both emotional and spiritual as he experiences a sense of relief, well-being and even euphoric "connectedness" with others:

> It was as if I had come back to life. I was born again…My feelings of euphoria went beyond simple optimism. The shell of protection that I had built around my emotions melted, and my defenses—a wall built of humor, acerbity, and cynicism—fell before a welling of emotion that was a total departure from my usual state of mind…The sharp edges of my self had become porous and weak. People could reach into me more easily, and they, in turn, were more vulnerable to me. (Murphy 2001, 42)

Murphy compares his new (temporary) state of happiness with both a "kind of religious experience" and a sense of community/shared purpose often experienced by those participating in political movements and activism such as the University Columbia strike of 1968.

However, such euphoric optimism does not last; on the fifth day after the operation, he wakes up to a “deep sense of fatigue” as he realizes that his paralysis has increased and he can “no longer raise [his] left foot”. At this point, Murphy’s upbeat mood turns “into depression” (46) and he begins to “think seriously about death”. But Murphy’s experience of paralysis, his “cloistered life of the wheelchair” and the consequential effects of “separation and isolation”, become overwhelming:

> The loss of spontaneity invaded my entire assessment of time. It rigidified my short-range perspectives and introduced a calculating quality into an existence that formerly had been pleasantly disordered...My chest muscles had atrophied…Talking for a long time tired me, and my voice had lost timbre and resonance. (76-80)

Although he is moved by the “physical” gestures (the light touch on the shoulder or arm) offered by medics, students and friends, Murphy feels that he is no longer part of that “different” species—those that he sees “hurrying along the streets” below his hospital window (126; 64-65). This highlights the more general plight of the ill and the disabled in western society, despite its technological advancements: “One can die very much alone in America, for the end often comes in hospitals, where the patient is attended only by medical people and life-support machinery”. Like those who share his paraplegic/chronically ill status, he realizes that he has “moved subtly from the center of my society to its perimeter” (111). Although Murphy struggles against negative stereotypes of paralysis, his new identity becomes contingent upon his defects whilst his “prior claims to personhood” have either been compromised or “radically altered”: “[We] have become aliens, even exiles, in [our] own lands” (111).

The Body Silent thus highlights the paralysed/ill person’s connection to “liminality” as defined by Victor Turner: “Liminality is likened to death, to being in the womb, to invisibility, to darkness” (Turner 1967, 95; Murphy 2001, 135). He explains that in his paralysed state, his “body closes in upon [him], so also does the world”:

> My spatial placement seems to mean less to me now, for…I am always anchored by inert flesh…I must continually fight this tendency for this growing passivity to overcome my thoughts. But there is a certain security and comfort in returning to my little cocoon…And it is at these times that my mind wanders farthest afield. In such deep quietude, once indeed finds a perverse freedom. (193-4)

Such thoughts prompt him towards suicide—“I began dreaming of suicide”—but he realizes that whilst “suicide is a simple matter for the able-bodied…it is a very difficult feat for the motor-disabled" (64-65). Murphy likens paralysis to "an allegory of life and entropy". For him, the paralytic's inertia is "symbolic of death itself; he is life's negativity…a kind of premature death in life" (229). Thus, he contends:

> Paralysis sets in motion a process of estrangement from others, from one's own body, and ultimately from one's self. It is a metaphor of death and a commentary on life. Disability does indeed have meaning, albeit one that is bestowed humanly. (223)

More optimistically, Murphy suggests that his own efforts to analyse the role of the ill person in society and "reconcile the sick person to his illness" redefine his one function as that "of the shaman", although unlike the shaman, he "seeks no cure, only comprehension". In concurrence with Freud et al, Murphy suggests that the apprehension of mortality "is a condition of our consciousness, a first premise of our sense of time, an axiom in our grasp of selfhood". Thus, Murphy's experience of paralysis and his contemplation of mortality suggest to him that "Death makes manifest life and all its value"; thus, death is not merely a "negation of life", rather death "creates and makes new life possible" (62-3).

Indeed, although Murphy defines the paralytic, quite literally as "a prisoner of the flesh", he suggests, "most humans are convicts of sorts". In his role as shaman, he "sees" the "walls of our own making", the restrictions of freedom and thought "thrown up by culture and annealed by our fears". Thus, I would argue that Murphy's text, like Antonio Gramsci's analysis of capitalist hegemony in his *Prison Notebooks* (1950; trans. 1970), through its personal and poignant account of paralysis, highlights the pernicious role of imaginative sterility and unthinking servitude to cultural practices, via the ossification (or freezing) of imaginative transformation, community and connectivity:

> This kind of thralldom to culture turned rigidified and fetishized is more onerous than my own somatic lifejacket, for it induces mental paralysis, a stilling of thought…To free oneself of the restraints of culture, to stand somewhat aloof from our milieu, and to re-find a sense of what and where we are. It is in this way that the paralytic—and all of us—will find freedom within the contours of the mind and the transport of the imagination. (231)

This freedom also seems to map onto his right to die as "loss of spontaneity" (Murphy 2001, 76) and his atrophied muscles, precipitate his "voluntary stillness", his "dying slowly"—and finally, his turning inward, a letting go.

> To fall quietly and slowly into total paralysis is much like either returning to the womb or dying slowly…the growing sense of stillness of the body invades one's apprehension of the world.

Jean-Dominique Bauby, *The Diving-Bell and the Butterfly*

In 1995, Jean-Dominique Bauby, the former journalist and editor of *Elle* (France), suffered a stroke at the age of forty-three. His autobiographical memoir, *The Diving-Bell and the Butterfly*, published in France in March 1997 three days before he died, presents a vivid account of the stroke, coma and subsequent condition of locked-in syndrome that he experienced. The French term for locked-in syndrome, *maladie de l'emmure vivant* or walled-in alive disease (Craig 2008, 146)— powerfully revisits Plato's image of the body as a "cage" or "living tomb which we carry about": "We are imprisoned in the body, like an oyster in its shell" (ibid., 145). As the text reveals, Bauby is internally alert, agile and conscious, but unable to move. As suggested by the "diving bell" in the title, his body is imprisoned; his is a "captive" body. Thus, his text is in many ways analogous to captivity and prison narratives—such as those published in America in the eighteenth and nineteenth centuries, but with no prospect of salvation, escape or liberation (Thomas 2000; Reed 1858). His body becomes a cage—or diving bell—out of which he can gaze. He cannot move; only be moved. He can only "see" within the boundaries defined by his physical location; he can only communicate via painfully laborious blinking of one of his eyelids. He is physically "immobilised" yet conscious. Consequently, his autobiographical work conveys a stifling sense of claustrophobia, subjection, disempowerment and medicalised (patient) identity.

Bauby's condition signifies the space between the living and the dead, absence and presence, subject and object. He exists, as Craig observes "on the margins of the animate and the inanimate" (Craig 2008, 147). His sense of self is not just "precarious" (as suggested by Butler) but exists uncomfortably within the realms of the inanimate, the "frozen" or the "freeze frame" (Butler 2006). Such a "frozen" life or vitality signifies the opposite of existence and thus occupies the locus of the uncanny. He has not passed from one state to the other—from the living to the dead—but remains inbetween. He has, in a sense, however, become a *dead* body: profoundly corporeal, corpse-like, un-living. The "body" that protects him (the shell that surrounds Plato's fragile "oyster") has become incumbant, a dead weight, coffin-like.

Just as Murphy had done, in his text published ten years earlier, Bauby's *The Diving Bell and the Butterfly* emphasizes one significant consequence of his paralysis—his profoundly transformed sense of identity and frustrated agency. This occurs on several levels: his social, professional identity; his relationship with his family and friends; and his ideas of *himself*—his own "sense of self". In his autobiography, this is indicated via philosophical musings:

> Just now I am struggling with the letter "I", a pitiful admission for an editor-in-chief. (Bauby 1995, 48)
> "Are you there, Jean-Do?" she [Florence] asks anxiously…And I have to admit that at times I do not know. (Bauby 1995, 49)

This alienation from his former "self" is vividly conveyed via his sudden chance upon his reflection in a mirror. Here he sees himself not only as a stranger, his previous "self" estranged, but as "monstrous":

> Reflected in the windowpane I saw the head of a man who seemed to have emerged from a vat of formaldehyde. His mouth was twisted, his nose damaged, his hair tousled, his gaze full of fear. One eye was sewn shut, the other goggled like the doomed eye of Cain. For a moment I stared at that dilated pupil before I realised it was only mine. (32-33)

In this re-visited "mirror-stage", Bauby sees himself as "horrific" other: a dead/preserved/terrifying specimen in a jar—not quite dissected but already "sewn" up by the embalmer. What he sees is a separation of *him* from him*self*[2] that is terrifying—a moment that resonates with Fanon's understanding of his bodily identity in the context of 1950s French racial colonialism:

> Consciousness of the body is solely a negating activity. It is a third-person consciousness. The body is surrounded by an atmosphere of uncertainty…
> "Mama, see the Negro! I'm frightened!" Frightened! Frightened!….
> I sit down…and become aware of my uniform. I had not seen it. It is indeed ugly…Already I am being dissected under white eyes, the only real eyes. I am fixed...On that day, completely dislocated…I took myself far off from my own presence, far indeed, and made myself an object. What else could it be for me but an amputation, an excision, a hemorrhage [sic] that spattered my whole body with black blood? (Fanon 2008, 111-112)

Trauma

Bauby's understanding of his reduced status instigates feelings of trauma—not only in response to his lack of mobility, but in relation to his sense of imprisonment, claustrophobia, diminished rights and at times, chronic pain. In a study of trauma entitled *Moses and Monotheism: A Memoir* (1937), Freud figured the "traumatic consciousness" as one of exile, amnesia, without language or discursive support, which registered a "loss" of identity or sense of self (Kaplan 2005, 44) For those suffering medical trauma, this split between the old and the "new" self can precipitate a sense of chaos, confusion and alienation—aspects often reflected by the abandonment of linear narrative forms and the prioritisation instead of complex, confused, fragmented forms that resist conclusions or resolution and are often seen as signifiers of literary modernism (Conway 110, 119). For the paralysed subject, the experience of bewilderment, grief and anger "divide[s] an individual's history into two", marks the "transition to disability" and establishes "enforced membership to one of the most discriminated against groups in society" (Morris 1997, 9).

Medical trauma, as Jenny Morris comments, "shatters a way of life" (ibid.). Bauby's autopathographical text reveals the ways in which trauma is "managed"—not only by sufferers themselves but also by "others"—medics, families, the "state", the law, film makers, directors. Yet whilst the political and ideological context within which traumatic events occur "shapes their impact" upon both the individual and the collective, it can also, as Ann Kaplan suggests, "produce new subjects" (Kaplan 2005, 1). Bauby's text exposes the complexities related to patient-doctor/lover/child/friend/colleague communication and "touch", as well as attitudes towards dying and "death-in-life".

Technologies of the Body: Paralysis, the Machine and Communication

Bauby—who describes himself as a "voiceless parrot", in his "nest" at the "dead-end corridor of the neurology departments"—can only communicate by blinking every letter of the alphabet with his left eye to an interpreter. Although he has not completely lost language / communication, his thoughts have to be painfully slowed down and reformed into "written" speech—letter by letter. This severely reduced form of communication isolates him from loved ones (many of whom cannot bear to see him so drastically changed anyway), and reminds us that all illness—including paralysis—"is a lonely state" (Frank 2001, 2). Conditions of living pivot upon rights to speech and mobility and as poststructuralists suggest, identity is embedded in and dependent upon, language. Bauby can only speak, protest, exclaim with the aid of a translator; he has no voice without his amanuensis and it is not surprising that she becomes his guardian angel, an interpreter of his S.O.S signals.

Lennard Davis' work, *Enforcing Normacy. Disability, Deafness and the Body* (1995) reminds us that divisions between whole/incomplete, able/disabled are artificial: "Wholeness is in fact a hallucination, a developmental fiction", part of the "very act of repressing the primal fragmentariness of the body" (Davis 1995, 175). Moreover, for those individuals who have suffered paralysis or "locked-in syndrome", machines and tools can be seen as extensions of the body—as exemplified by Professor Stephen Hawking, who uses a speech-generating device to supplement or replace speech. The intimate relationships between human life and technology are most clearly demonstrated in performances such as Stelarc's, "Muscle Control Electronically" (2007a) and "The Body is Obsolete" (2007b); and Donna Haraway's theoretical work on cyborgs, in which "couplings between organism [humans] and machines" provide revised maps of "power and identity": "Bodies have become cyborgs—cybernetic organisms—compounds of hybrid-techno-organic embodiment and textuality. The cyborg is text, machine, body and metaphor—all engaged in…communication" (Haraway 1985). In fact, Bauby's narrative, together with his efforts to communicate in *binary* code (blinks for yes/no), correlate with concepts of the "posthuman body" as transcending the constraints of physical matter or corporeality, to a rethinking of human identity in cyberspace and/or in a relationship between humans and intelligent machines:

> This vision is a potent antidote to the view that parses [analyses/breaks down] virtuality as a division between an inert body that is left behind and a disembodied subjectivity that inhabits the virtual realm…By contrast…it is not a question of leaving the body behind but rather of extending embodied awareness in highly specific, local, and material ways that would be impossible without electronic prosthesis. (Hayles 1999, 290-1)

Paralysis, Place and Rites of Passage

After his stroke, Bauby was transferred to Berck-sur-Mer, a coastal region in northern France. This positioning further reinforced his "in-between" state—between land and sea, living and dead. He had not yet crossed the River Styx to the underworld, but hovers at its brink; he has not yet "passed". Bauby's horror of entrapment or premature embalmment, is compared with that of his elderly father, similarly "trapped" in his apartment, and his friend on the plane on the way to Palestine—but whereas both of these individuals can articulate their experiences and communicate with others, Bauby's physical and linguistic barriers become almost insurmountable. His pain is not quantitatively observable; communication of that pain demands exhausting effort that mitigates spontaneity and depends upon others for translation. When Bauby looks in the "mirror"— not dissimilar to Lacan's mirror stage—he describes his eye as the "doomed eye of Cain", a symbol of death. However, the eye is also signifier of vision and imagination. It is this imaginative eye that allows, firstly, a new consciousness of himself; and secondly, allows him to transcend the limits of the body, via his memories and fantasies (and imaginings) and to be transported "elsewhere". In contrast with the darker chapters in Bauby's book (such as "Wheelchair", "My Lucky Day", "Through a Glass Darkly"), the more positive and humorous chapters (such as "Empress", "The Sausage", "Wax Museum") signify "flights" of freedom and imagination—memory, fantasy, even imagined communities—and thus fulfil the metaphor of the "butterfly" as suggested by his title (Andersen 1991). This new consciousness entails a stoical acknowledgement of a split from his former self (Church 2008).

Thus, although Bauby's autopathography constitutes an elegy, one which mourns the passing/loss of the energy and vivacity upon which life revolves; vivid memories of the past and fantasies of the future dominate his sense of the self in the present. On the one hand, therefore, his paralysis defines him as "in-valid" in relation to the dynamics of the social world, whilst on the other, Bauby's agency (as author and critic) and "being" become increasingly "virtual" and textual. Yet censorship (of self and within text) still exists, and one wonders whether the close coincidence of the publication of Bauby's text and the end of his life, suggest his exertion of the individual's "right"— to die.

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[1] http://www.mssociety.org.uk/what-is-ms/information-about-ms/about-ms

CHAPTER TWELVE

WATCHING OTHERS DIE: *DYING AT GRACE* (2003), SPECTATORSHIP, AND THE ETHICS OF BEING MOVED

MICHELE AARON

In Elaine Scarry's seminal text, *The Body in Pain* (1983), she revealed how the inadequacy of language, choked back through pain, through stilted and stifled communication, kept the experience of pain inside, interiorised. Pain was understood as both inexpressible and unshareable. In previous work, I extended this to dying and explored how film, or more specifically its representation of mortality and bodily decline, translates and transforms this inexpressibility (Scarry 1983; Aaron 2014). Through a focus on mainstream cinema, a cinematic language for dying was distinguished albeit one that sustained taboo, and a limited and prejudicial, vocabulary. In what follows, I consider the potential of film to represent dying differently and provide a forum for pain and dying to be externalised and, most importantly here, shared in, on- and off-screen. Film might be, as Alison Landberg argued, "a technology that could generate empathy", but how does it use it? (Landsberg 2004, 150). Is empathy enough, as a term and as an experience, to describe the spectator's response to others' suffering, or to bridge the fraught, and constantly reinforced, distances separating the healthy and the frail, those in ascendancy and those in decline, those watching as others die? And what would, or should, this bridge afford or enable? This chapter explores how film conveys the experience of dying to allow it to be shared. The emphasis here is on this sense of a *shared* experience, on a relationship between subjects on- and off-screen. What sharing means or could mean will be explored as we reconcile the imbalances—and prescriptiveness—inherent in this relationship to reckon with the necessarily ethical questions surrounding our involvement in others' deaths.

If, as I have argued elsewhere, mainstream fiction film disavows, distorts and displaces dying, and if, in doing so, it confirms the values, salves the conscience and the death fear of the spectator, this chapter seeks an alternative (Aaron 2014, 99-126). In seeking this alternative, I focus on a fairly small but growing number of films that, rather than turn away from death, rather than deny, deform or degrade its realities, turn towards dying, real dying, and dwell there.[1] Such films include the documentaries *Dying* (Michael Roemer 1976), *Near Death* (Frederick Wiseman 1989), *Dying at Grace* (Allan King 2003), *Silverlake Life: The View from Here* (Peter Friedman and Tom Joslin 2003) and *How to Die in Oregon* (Peter Richardson 2011). These are neither mainstream nor marginal films nor a complete list.[2] I will focus here, however, on the acclaimed but relatively unknown Canadian director Allan King and his penultimate "actuality drama", *Dying at Grace*.[3] This film offers an extraordinary commentary on the capacity of film to represent dying, to express it and to share it, and to do so ethically, that is with an eye or, better yet, an ear to the experience of dying and to our part, our de-privileged part, in its lesson.

Dying at Grace provides an unflinching and metaphor-free record of five people's final days at Toronto Grace Health Center. King's commitment is to the individual's experience. He captures rather than tames death. His style is confrontal: it faces head-on and up to its topic. This confrontation will prove neither frontal nor solipsistic, in Levinasian terms, nor heroic in its impulse or promise. The film starts with titles on a black screen, as prologue and dedication. The first: "This film is about the experience of dying". The second: "Five patients in a palliative care ward for the terminally ill agreed to share their experience in the hope that it would be useful to the living". The subsequent frames dedicate the film to these five, to their family and friends and to the staff at Grace. As well as redressing what John Tercier calls contemporary culture's "paucity of experience" (Tercier 2005, 22) when it comes to dying, the first title distils King's intent, and perhaps signature: experience is all here. What the titles make primary is that the experience of dying and its lessons are owned by the dying themselves. This defies the object status usually accorded them: instead, their status as subjects, as sovereign centres of the narrative, and the denial of objectification and dehumanisation underwrite the film. The titles also suggest that the lessons of dying are for the living: they are not for the grieving, for the survivor left behind, but for an unprivileged and unspecified group elsewhere. In this way, *Dying at Grace* embarks with unconventional aplomb: in place of directorial accreditation, the film centres its "characters"; instead of the trauma of bereavement, dying is to be a gift to the audience. The experience of dying gives and is used: if it is an experience, it is a co-experience. This is not to undermine the authority of the dying individual or to privilege the activity of the spectator but to emphasise how dying must be thought of as somehow social or, as Alan

Kellehear puts it, as a "shared set of overt social exchanges between dying individuals and those who care for them" (Kellehear 2007, 253).

Implicit in the opening titles, too, is the consent of those dying to the film that is being made. The hot topic historically in ethical filmmaking and documentary theory has been the question of consent, and with it fairness and respect, and this is especially true in relation to watching death and dying.[4] However, the ethical approach here moves from these issues to the question of privilege and sovereignty in our position as spectator, and to an understanding of how the spectator is implicated in and impacted by the suffering and vulnerability of the other being watched without—and this is crucial—collapsing that understanding into solipsistic reassurances or discourse. This ethical film criticism is grounded in Emmanuel Levinas' "first philosophy", which defines subjectivity in its reach to the other rather than the self. In this model, the subject is constituted *through* responding to the other (and specifically to his or her vulnerability) and *as* an obligation arising from the other's difference or alterity (Levinas 1989). This obligation is so formative because alterity, or the other's difference, underpins intersubjectivity and is inherently compromising. This obligation "arises from our most primary, and unavoidable, implication in the other's potential death: the murderous impulse that frames self-interest" (Aaron 2007, 111).[5]

Key here is the way in which King provides the experience of dying as a co-experience, grounded in the intersubjective encounter in which death is at stake and the other is not to be reduced to the same. This non-solipsistic, de-centring and de-privileging approach is primary. It specifically targets the problem of that "I" at the centre of the ethical: that relentless, always eventual, return to the same-old story that is, to the priorities and psyche of the western spectator. This problem isn't strictly "the narcissistic emotion of modern humanism [caring only for people like us]" (Chouliaraki 2006, 14),[6] as Lilie Chouliaraki puts it so succinctly, but a more invidious and no less common version of it: the solipsistic unconscious of modern humanism which cares for those not like us in order, ultimately, to salve or save our souls (Chouliaraki 2006, 14). This unconscious finds a natural home in Hollywood—in its countless images that make us root for the underdog or cry for the victimised and ultimately commend us for doing so—but something else is going on in *Dying at Grace*.

In King's unflinching and un-metaphorical record of five people's final days, his commitment is to the individual's experience, which he declares immediately. *Dying at Grace* provides no centred or privileged character or viewpoint. Instead of identification with, or objectification or abjectification of, the dying, we are simply moved through and, most importantly here, moved by what is going on. This moving image reaps its return not through the string playing or string pulling of Hollywood but through something slower, stiller and, like dying itself, less regulated. Eda seems to be recovering over most of the film's course, then suddenly declines and dies: "Dying follows its own stubborn narrative", says Jackson of the film, it "won't be 'directed'" (Jackson 2010). Neither is there, then, a centred, rarefied, creative voice: the accoutrements of authorial imprint are dispatched, and overwhelmed, by the precedence of as raw a record as possible.

Our being moved by the film is not a signal of sympathy or empathy, of distant care or compassion. And it is not a vehicle for sculpting sentiment in the service of ticket sales or public opinion or political ends. Such things, as I will clarify below, are the armaments of unconscious solipsism, of the constant return to the concerns of the Western self. Instead, this moving image is an encounter with what I want to call raw life, but how best to interpret it? I want to consider a number of ways that this kind of encounter has been thought about in order to assemble a term (or terms) that afford us greater insight into the capacity of cinema to share death with us. Such a term must avoid commending or comforting the spectator, or returning him or her to the concerns of the self rather than of the other. It must, in other words, be ethical. Such a term might provide intimacy but not at the expense of objectivity. It might be subjective but never exclusive: universal and always particular. It might also, ultimately, speak to the specificity of film and therefore contend with cinema's conventional rhetoric as well.

In speaking of *Dying at Grace*, King made clear that the experience and the lesson of dying were inherently linked, that one must "[put] oneself into the experience in some emotionally vivid way, so one can come to terms with it" (Allan et al. 2012). We are put into, we enter, the experience through the observational mode. The paring down of filmmaking into long takes and close-ups with broad access to rarely seen events immerses us in the world of the ward and the dying individuals. We are privy to highly personal events but with discretion: the bodies here remain intact and retain their dignity but without precluding their embodied vulnerability. Close-ups and long takes chronicle the hair on Richard's face, the stroke of Carmella's hand, each inhalation of Eda's until her last. This intimate but disinterested engagement with the individuals is "emotionally vivid" because of the place of the personal and even lyrical within it.

Intimate but disinterested, the experience of dying on-screen does not become our own; it is not prosthetic. This negotiation of distance and absorption without co-option is fundamental. Our own dying is promised, of course, in the wages of time, the seasonal shots of Toronto and passage of night and day, but also by a machine's beeping, which punctuates the film with false infinitude. But the experience of dying does not become our own for to do so would be to reduce their experience to ours: we can share in it without identifying with it or owning it. It is a co-experience though we have very different parts to play. It is an embrace, not a levelling, of difference. In and through that embrace, we feel the magnitude of the events without training them to our own interests.

Hollywood, in contrast, strives for sameness in its protagonists: we draw close to, identify with, them in their familiarity. Alison Landsberg has made some interesting points about sameness and "deep feeling" in her distinction of spectatorial empathy from sympathy. Empathy for her is ethical because it operates "beyond the immediacy of one's own wants and desires" (Landsberg 2004, 149). It is encouraged by what she calls "prosthetic memory", the way in which the cinema spectator, as the key example in modernist culture, "sutures him or herself into a larger history…[and] takes on a more personal, deeply felt memory of a past event through which he or she did not live" (Landsberg 2004, 2). Sympathy, however, does something else and is less ethical for it. It is, for Landsberg, a "wallowing in someone else's pain…[An] act [that] can be imperializing and colonizing, taking over, rather than making space for, the other person's feelings" (Landsberg 2004, 149).

Sympathy's reflexive mechanism or return to self is revealed as effusive and transparent. However, I would argue that empathy's is quieter, refigured, but there nevertheless and charged, instead, with neo-imperialism or neocolonialism. Sympathy wears its self-indulgence openly, is more blatantly narcissistic, but empathy is solipsistic still. The socio- or geopolitical price is the same.

Ethical film criticism is inherently political. Levinas' first philosophy, a first politics if you like, marked the violent stakes of the inevitably *inscribed* difference between the self and the other. In more common terms, we might note the constant "asymmetry of power between the comfort of spectators in their living rooms [say,] and the vulnerability of sufferers on the spectators' [cinema or] television screens" (Chouliaraki 2006, 4). Watching others die always involves a pronounced imbalance: the gaze may not be presumed healthy—*Dying at Grace* does not construct the well gaze of fiction film, and King anticipated an audience in palliative care—but neither is it on this cusp of death.[7] I am pointing here to how the (ostensibly normative) dying individuals in King's film receive excellent treatment which they are extremely privileged, in the bigger picture, to have access to. Theirs is hard to see as a "place in the sun" (Levinas 1989, 82), but it is a much better experience, if not death, than so many have (from starvation, civil war, abuse, etc.). So, while *Dying at Grace* confounds the cinematic language of dying, rife in mainstream fantasies, it still provides a forum for seeing death, and experiencing it, untroubled largely by class, or nation, or race, or gender or other social specifications. This kind of co-experience is always already political therefore, and, always already ethically charged.[8]

Theirs is not "bare life" either. Giorgio Agamben made the important distinction of the abject figure of the "living dead" in his theses on the deathly workings of sovereign power.[9] Describing the Muselmann of the concentration camp he wrote: "[m]ute and absolutely alone, he has passed into another world without memory and without grief" (Agamben 1998, 185). While the five dying individuals in King's film inhabit a similar space, theirs is not a "life that does not deserve to be lived" (ibid., 137), or, to be grieved, as Butler has put it (Butler 2009). They have not been reduced to this state by others, are not afflicted from elsewhere. Neither has the (necropolitical) system cast them out, removed their worth and rights and rendered them inhuman. Raw life, then, echoes this other inherent asymmetry: not just between the spectator and the near dead in *Dying at Grace* but between them and the near dead of, say, the Holocaust. In this way, "witnessing", the ethical outcome of attention to bare life, and its political project, is *not* the modus operandi of *Dying at Grace*, nor what spectatorship enables here. The five people in King's film are "just" dying from terminal illnesses. The imprint of sovereign power does, of course, mark the dramas of dying of even the "oldest" citizens—life is always subject to it, hence the critical valency of Agamben's work—but, crucially, by degree. Politics, though always already at play, recedes, and the full weight of the potentiality of the moving image can come to the fore.

With sympathy dispatched, empathy flawed, and asymmetry recurring, what further ways might there be of understanding the powerful feelings engendered, and the borders crossed, by watching others die? Chouliaraki promotes "connectivity" and "solidarity" to describe an optimal, ethical, spectatorship. Though she speaks in similar terms—of pity, reflexivity and narcissism—she has a specific focus on news reports of "distant suffering" and refiguring the public sphere in order to proliferate humane responses to global calamity. *Dying at Grace*, however, is not a window on distant suffering, on a geopolitical elsewhere, but the question of the distance between the sick and the well, the subject(s) on-screen and off, remains fundamental. Indeed, though the genre and goals differ, the shared landscape of the ethics of watching others die renders Chouliaraki's, as well as others' work from different disciplines, both compelling and compulsory frames.

"Connectivity" usefully bridges the distance between individuals, without prejudice or priority, and "solidarity" lends it the political and emotive edge, even as it keeps things fairly clinical. But Chouliaraki warns, too, of the by now familiar problem of one circuit of connectivity being privileged: "It is not connectivity to the 'other' seen on the screen that counts as the purpose of mediated experience, but the connectivity to fellow spectators…[as a] self-referential loop" (Chouliaraki 2006, 27). In contrast, Anat Pick's meditation on the ethics of vulnerability, as a "creaturely poetics" of film and literature, also utilises connectivity but an embodied connectivity that bypasses such loops. For Pick, "creatureliness" is the term of choice for the material vulnerability describing connectivity (Pick 2011). hough her interest in the troubled vulnerability of life (and the genocidal passions associated with it) is focused on the human/non-human distinction, her discussion is illuminating, nevertheless.[10]

For Pick, the embodied contact of connectivity is achieved through an "attentive gaze" which reveals our common creatureliness and "cannot help being 'innocent' to the extent that it sees while remaining unattached to (uninvested in) its object" (Pick 2011, 160). This attentive gaze, then, is relatively neutral: implicitly impersonal and outside asymmetry yet forged in a shared embodiment. This will to neutrality comes not at the expense of the body, politic, or self-cleansing soul. Neither well, nor male, nor objectifying or abjectifying, this gaze contravenes conventional looking. Its mode of connection is beyond the normal regimes of sentiment, and power, and vision, but makes corporeal contact nevertheless. Such contact, in *Dying at Grace*, comes with the facial close-ups, the caress, the tears and breathing: an attention to detail that is professional and affectionate, corporeal but not sensorial.[11] And it exceeds the contours of life: the nurses' touch continues beyond the individual's capacity to register it, whether smoothing the brow of the near dead or an early "God bless you" uttered in the mortuary.[12] It is, in this sense, unrequited.

Where sympathy is feeling as the other, and empathy is feeling for the other, we are edging ever closer to this sense of feeling with or towards the other. This feeling involves connection plus emotion without narcissism *and* with shared vulnerability or exposure. *Dying at Grace*, I believe, achieves this final step as well. It does this through what I want to call its "de-cinematicism". Previous discussions of the ethics of spectatorship, including my own, have focused on the metacinematicism of contemporary films about suffering and how they render the spectator self-conscious and accountable through disrupting the seamlessness, and seemliness, of narrative (Aaron 2007).[13] Such tactics often afford a celebration of cinema or the individual. Dependent, as they are, on self-reflexivity, this is, by now, unsurprising. Decinematicism, in contrast, is not replenishing. It dismantles the spectator's safety nets in moves that are far more radical. *Dying at Grace*, as illustrated above, breaks with numerous filmic conventions, not least those attending death, but it also involves a pronounced undoing of film's basic or ontological tenets.[14] In capturing dying, dying as a co-experience, but also and most importantly now, death as process, the film unravels the very contract of cinema underlying spectatorship.

Sobchack suggested that documentary film fails to secure and record death but, in *Dying at Grace*, it is not just the final moment that is captured that constitutes death but a longer and gradated journey.[15] The individual's exit from the world of the living is, in other words, a process. It happens in stages but, more than this, as the terms "deathwatch", "brain dead", "being kept alive" or even CPR (cardiopulmonary resuscitation) attest, it possesses a degree of indeterminacy (rather than ineffability). In *Dying at Grace*, death is the "won't be directed" decline of the individual with bad nights and with "rallying" en route. It is also a *final* furlong that is marked by the cessation of cognition, when the dying individual ceases to be able to engage with others, when communication, awareness, agency and even subjectivity recede.

We receive various visions of this state of raw life in *Dying at Grace* but it is especially marked in two key scenes: the decline of Joyce and the death of Eda which closes the film, where the former works as a kind of prerequisite for the latter. As Joyce journeys ever closer to death, her gaze becomes more fixed and blank. In the middle of the film, we sit with her for quite some time and this progression is clear. The camera is positioned so that the emptiness and impenetrability of her gaze are enhanced by the reflection of the window's light in her glasses.

Fig. 12-1 The Unmoving Image of Joyce, *Dying at Grace*

Immobile and opaque, this shot endows Joyce with an automaton-like presence, compromising her human subjectivity further. Compromised but not evacuated, the defamiliarising of Joyce does not dehumanise her or the dying subjects here: we are too soldered on the co-experience, the cycle, of living and dying to fall for that. But it does "(positively) awaken [us] to human uncanniness" (Pick 2011, 159). Where, for Pick, this product of the blank gaze is integral to a creaturely connectivity, here the defamiliarisation affords, after Victor Shklovsky, a productive estrangement from the otherwise known (Shklovsky 1990). It enables us to see and feel again and afresh—beyond what we assumed and the tyranny of vision—as the very potentiality of cinema that I'm pursuing here.

The blank and blind state of raw life in *Dying at Grace* is inevitably affected, if not determined, by drug treatments. The perhaps "medicated blankness" (Catsoulis 2007) is, however, potent not simply as a counterpoint to Hollywood expressionism but as the individual's involuntary internality, a withdrawal that ruptures the conventional presuppositions of cinema. What I mean by this is that our long stare at raw life contravenes and confounds the unconscious and, one might add, ethical, contract underpinning spectatorship: the spectator and the film have been defined, historically, by a relay of looks and suspension of belief but this ceases to hold true in King's film.

Foundational film theory in the 1970s saw spectatorship as a tacit agreement, a kind of contract, between spectator and film spectacle: the spectators "forget" they are watching a film, and the film, and its actors or characters, "forget" they are in one. In more explicitly psychoanalytical terms, both parties disavow the fantasy—they cover over the absent real with a set of appealing and distracting images—to indulge in it fully. According to Christian Metz, the principle player in this call for the fetishism of cinema, the unconscious agreement runs in the two directions: "I watch it, but it doesn't watch me watching it. Nevertheless, it knows that I am watching it" (Metz 1982, 94). In this way, the relationship between the spectacle and the spectator is revealed as "[an] active complicity which works both ways" (ibid.). This contractual dynamic, and active complicity, on the part of the film's subjects, translate, overtly and ethically, in *Dying at Grace* into the consent of those dying to the film being made, as well as the choice of the spectator to watch. And the anxiety underpinning fetishism, translates from the general fear, hence disavowal, of death in mainstream fiction films, to the overt "coming to terms" with it here. To agitate the question of consent further, we are reminded by Sobchack that the spectator's consent is especially, and ethically, heightened when watching someone die: "*Before the nonfictional screen event of an unsimulated death, the very act of looking at the film is ethically charged*" (Sobchack 2004, 244).[16]

In *Dying at Grace* what happens in these moments of raw life, of withdrawal, of blankness, is that the dying individual stops "knowing" that I'm watching. In so doing, a chasm opens up between the contractual obligations of the film, the co-experience and the process of death. The contractual dynamic falters, the reassuring (fetishistic) mutual complicity ends. The spectator is left without psychic or ethical scaffold. This chasm affords a space which operates here as the very site of the potency and awe of exposure.

What is more, the dying individual stops being able to acknowledge the spectator's, or my, look to reciprocate in a more conscious way, too. The light bouncing off Joyce's glasses is a forceful image of this. In her discussion of the rare documentaries that actually provide an ethical vision of real dying, Sobchack singled out the "humane gaze" of Roehmer's *Dying* and Friedman and Joslin's *Silverlake Life*. "Marked by its *extended duration*, the humane gaze…engag[es] itself directly with the direct gaze of its dying human subject, who looks back" (Sobchack 2004, 253). The takes are long in King's film but the dying individuals in this observational documentary never address the camera directly. They are also often shot in profile, or asleep, and rarely centre-frame or frontally. In the concluding long take of Eda reaching death, her ability to sustain life, rather than cognition which has long passed, contracts so that even the rebound of breathing ceases. This scene provides an intense culmination to the film and realisation of the point, and poignancy, of "no-return". There is, however, more than "an agreed-upon *complicity*" between the dying subjects and the filmmaker (ibid.). Indeed, King does not depend upon this humane looking back for his ethical approach. His purchase on humanity exceeds Sobchack's distinction of the two films and, more importantly, an ethics proven, or at least heightened, through consent-as-reciprocity. Arguing for the creatureliness of the blank gaze, Pick locates the returned look within the "narcissistic economies of looking" (Pick 2011, 159) and, in so doing, reminds us of the larger stakes, and broader sweeps, of mainstream culture: "Humanity and personhood in film are partly constituted via…the network of visual commerce by which the self replenishes its powers through another's look" (ibid.).[17]

The spectre of solipsism lingers still. This is not to devalue Sobchack's discussion at all, not least because it appeared before the surge in documentaries about dying that King's film was part of. What is more, *Silverlake Life* was, in many ways, the breakthrough film, and now has been widely acknowledged as such.[18] But where Sobchack focuses, necessarily, on how humanity is ethically constituted through that direct gaze back, King's film represents an exciting possibility of cinema providing something else. Something not so much "revelatory" (Derrida 1993, 127)[19] as unconditional in its crossing the additional frontier between the subjects on- and off-screen, taking that aforementioned final step and then some: of feeling towards but *without* the other.

> In opposition to the humanist demand that the other look back at me as the condition for her claim to recognition and power, ethics perhaps begins with the blank gaze. For what is ethics if not my seeing without being seen—my unrequited attention? (Pick 2011 159)[20]

Where, as Peggy Phelan argues of *Silverlake Life*, the representation of dying "allows us, at last, to learn a richer vocabulary for the present tense" (Phelan 1997, 21), for Butler this "keener sense of the value of life, all life, [must] take hold…in order to oppose violence" (Butler 2004, xviii-xix). This chapter has suggested the potential of cinema to share dying with us, and in a way that is meaningful in interpersonal, humanistic and, therefore, ethical terms. Such terms recognise the inevitable place of politics within this: the price of "my place in the sun" and of the "different ways in which human physical vulnerability is distributed across the globe" (Butler 2004, 32). And so we come back to Scarry who sketched a very similar sense of the high stakes of the expression of pain and, I still add, of dying: "The failure to express pain [and dying]…will always work to allow its appropriation and conflation with debased forms of power; conversely, the successful expression of [them] will always work to expose and make impossible that appropriation and conflation" (Scarry 1983, 14). What is more, *Dying at Grace* opposes the "debased powers" of the idiomatic and redemptive trajectory of mainstream representations of dying, too. Instead of evading and mystifying death or sustaining its wondrous ineffability, it renders it “natural and nameable” and even knowable (Sobchack 2004, 232). It offers, perhaps, not a debased but a “sort of sacred recognition of life’s value as material and temporal” (Pick 2011, 3).

Dying at Grace confounds consent and the humanity of the gaze, confounds them in order to rescript and revitalise them. Where the unrequited act of the dying individuals, the “gift” noted of those opening titles, was the prelude to the film, the spectator of *Dying at Grace* reciprocates in kind. This ethics of spectatorship as sharing, post-consent and unconditional, represents a zone of raw contact between the self and others where cinema affords individuals an unscripted sense of their place in the world and in relation to the rest of humanity: the awe of exposure, self-conscious but never self-indulgent. It also represents a radical departure from previous debates. It squares with Levinasian analysis, which prioritises communion beyond the visual or frontal field, and depends upon an always already political consciousness. But it also breaks with such analyses, in that its focus lies with watching the natural, neutral or “unexceptional” vulnerability of others rather than that animated by atrocity, necropolitical violence or interpersonal pain.[21] In this way, the ethics of spectatorship and the potentiality of cinema it illuminates root the representation of dying unsolipsistically within the truth of art rather than the traumas of history or politics.

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Notes

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[1] There has been a surge in the last decade or two in the production of made-for-television documentaries on end-of-life issues that centre on dying and even show it. Directly linked to current debates, and legal moves, surrounding assisted dying in the West, this surge sits within a more pronounced addressing of mortality and death practices in the public sphere perhaps as a result of AIDS, and shifts in visual culture, but certainly of demographic changes.

[2] Other, more hybrid, films of note, include: *Lightning Over Water* (Wim Wenders 1980); *Blue* (Derek Jarman 1993); Maurice Pialat's *La gueule ouverte* (1974); Mike Nichol's *Wit* (2001) and Michael Haneke's *Amour* (2012).

[3] Jean Renoir called him "one of the greatest film artists working today" and John Grierson was an admirer of his work. His films won numerous awards and in his long and productive career he headed the Directors Guild of Canada and received its Lifetime Achievement Award in 2006.

[4] See Vivian Sobchack, "Inscribing Ethical Space: Ten Propositions on Death, Representation and Documentary" in Vivian Sobchack, *carnal Thoughts: Embodiment and Moving Image Culture* (2004).

[5] Sara Cooper has spoken similarly of this different ethical approach in her focus on films which might "resist the reflective mechanism that would refer one back to oneself or one's own world", and in her use of Levinas "whose work is concerned with an inability to reduce alterity to the self-same" (Cooper 2005, 8).

[6]. Brackets in the original.

[7] For a discussion of the healthy gaze, see the first chapter of Laura Tanner's *Lost Bodies* (Cornell University Press, 2006). King speaks of this audience in his discussion of the film on TVOntario.

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[8] As Fanon reminds us: "There is of course the moment of 'being for others' of which Hegel speaks, but every ontology is made unattainable in a colonized and civilized society" (Fanon 1967, 109)

[9] See Giorgio Agamben's *Homo Sacer* (1998); *Remnants of Auschwitz* (2002); *State of Exception* (2005).

[10] See also Laura Tanner's emphasis upon the "shared vulnerability of embodiment" customarily disavowed in Western culture but exposed through the defencelessness of the dying, in *Lost Bodies* (2006), p.11.

[11] I am distancing this film's intimate disinterest/corporeal detachment from the "corporeal implication of witnessing" in Hallas' analysis of AIDS film (2009, 217), and its expressive non-literal "face" from haptic preoccupations of desire-fuelled avant-garde films, see Marks, *Touch* (2002).

[12] Judith Butler favours the term "touch" within her political discussion of "common human vulnerability", though she uses it very differently to Marks, see *Precarious Life* (Verso, 2004), p.30.

[13] See for example, Michele Aaron, *Spectatorship: The Power of Looking On* (Wallflower, 2007).

[14] It can be thought of de-cinematic in other ways too: in terms of its rejection of other film conventions especially as they pertain to depicting dying.

[15] It is a journey that puts pressure on the technology clearly—hence the failure in the past—and on ethics (hence *How to Die in Oregon* not showing it, being deliberately outside the house).

[16] Emphasis in the original.

[17] Pick is clear to trouble "reciprocity", distinguishing this mainstream narcissism from a more creaturely connectivity.

[18] See discussions of it in Peggy Phelan, *Mourning Sex: Performing Public Memories* (Routledge, 1997) pp.153-173, and Roger Hallas, *Reframing Bodies: AIDS, Bearing Witness, and the Queer Moving Image* (Duke University Press, 2009).

[19] For more detailed use of this, see Saxton, *Haunted* (Wallflower, 2008), p. 95.

[20] In contrast, key to Sobchack's distinction of the two films is not only the complicity but even love between the filmmaker and the dying individual, see "Inscribing Ethical Space" (2004, 253).

[21] See, for example, Sarah Cooper, *Selfless Cinema?* (Legenda, 2005).

PART III

ART AND MOURNING

CHAPTER THIRTEEN

CLOTHES FOR DEATH / ODJEĆA ZA SMRT
A VISUAL ESSAY

MARGARETA KERN

In my project "Clothes for Death", I photographed and interviewed women in Croatia and Bosnia-Herzegovina who set aside their own funeral clothes, a custom still practised predominantly among the region's Orthodox Christian and Roman Catholic communities. This series of intimate portraits respectfully engages with the lives of sitters and quietly opens spaces within the image for contemplating the inevitable.

Fig. 13-1 *Liza* (Donja Vrba, Croatia), 2006

Fig. 13-2 *Mila* (Banjica, Bosnia and Herzegovina), 2007

Fig. 13-3 *Jovana* (Nevesinje, Bosnia and Herzegovina), 2007

Fig. 13-4 *Cvijeta* (Banjica, Bosnia and Herzegovina), 2007

Fig. 13-5 *Mara* (Orubica, Croatia), 2007

Fig. 13-6 *Julka* (Banjica, Bosnia and Herzegovina), 2007

CHAPTER FOURTEEN

DESIGN OF DEATH

NIKKI SALKELD AND ASHLEY RUDOLPH

We are Senior Lecturers in Graphic Design at Falmouth University and our research project, *Moth*, is about design and death. Graphic design is about communication, making sense of complex information, using systems and hierarchy to create meaningful solutions to problems and questions. Established design process underpins and documents that journey, questioning how visual communication designers can contribute to end-of-life matters. We see ourselves as emerging researchers in this field with an expertise in graphic design and an interest in graphic anthropology. Our interest in the ways in which design shapes, and is shaped by cultural values and social practices, has a particular relevance to our understanding of the "design of death". We want to produce work, which can facilitate problem solving in the context of death and death studies and create "tools" in order to help articulate process. The *Moth* Project focuses upon the importance of ideas as triggers of creativity, as devices for narrative and as loci for opportunities of chance and transition in the context of loss and bereavement. In addition, the *Moth* Project explores metaphors embedded within layers of meaning specific to individual "readers" (those who have experienced bereavement or are interested in contemplating mortality) and societal conventions and traditions. To date this dialogue has taken the form of a series of practical workshops and an exhibition, which explore contemporary attitudes towards death and mortality through visual language and typographic experimentation. Until recently, our "readers" were from a fairly narrow demographic (undergraduate design and fine art students), but our recent work has included international partners who are keen to explore these ideas and create new creative partnerships. The *Moth Project* was initiated in 2011 after a conversation with a Norwegian student following the massacre on the island of Utoeya, during which Anders Breivik slaughtered sixty-nine people (the majority of whom were teenagers) after detonating two bombs in central Oslo which killed a further eight victims. This student reflected upon the lack of suitable visual symbols available that could be used to articulate universal sympathy in the context of death and bereavement. This conversation prompted inspiring questions about visual signifiers of mortality and, in effect, constituted a potential design brief. At the time, most of the social media messages posted in response to the massacre employed the heart symbol. This appropriation of a signifier of love seemed inadequate and highlighted our culture's inability to discuss death as freely as we discuss love. The *Moth Project* suggests that we become visually mute when confronted with grief and mourning and that our understanding of and relationship with death is both intimate and complex. Does an adequate visual symbol for death exist beyond the traditional conventions of the Christian cross and the morbidity of the skull?

Perhaps the uniqueness of a death together with a bereaved individual's specific circumstances prompts the need for a particular or unique symbol. The significance of the poppy for example, serves as a lasting visual memorial to those who died in World War One and later conflicts. Symbols can change over time according to social, cultural and political beliefs, values and trends. Signs employed in the past can become regarded by modern audiences as inappropriate or "primitive" and their context and meaning lost. The *Moth Project* explores the relevance, significance and potential re-launch of traditional symbols as well as the creation of new ones, some of which explore broad communication opportunities, whilst others may be bespoke to a specific "community" or event. In other words, the *Moth Project* initiates a set of tools in order to provide a visual language and typographic legacy, one that acknowledges a fascinating, and diverse heritage of death symbolism, but one that also seeks to prompt dialogue and bring discussions of death and mortality to the surface.

As designers, we endeavour to decode meaning and understand the context in which ideas are received in order to communicate appropriate messages adequately. Audiences are diverse and complex however, and we are aware that symbols can have significantly different meanings to different groups dependent upon ethnicity, religion, gender and/or age—but also as a result of individual personal experiences and relationships.

In his book, *Visible Signs. An Introduction to Semiotics in the Visual Arts* (2010), David Crow writes:

> All that is necessary for any language to exist is an agreement amongst a group of people that one thing will stand for another. Furthermore, these agreements can be made quite independently of agreements in other communities. (Crow 2010, 18)

Designers understand the notion that materials, artefacts, the means of production and design aesthetic carry meaning and value within the context of communication. However, beyond the function of an object or the legibility of a typeface, emotional content needs to be considered. A typeface, for example, has particular characteristics exclusive to its identity, and certain characteristics can have associations on conscious and unconscious levels which can communicate specific messages.

> I can hear Switzerland when I look at Helvetica. And when the Basque nationalist movement began to establish itself, at the end of the nineteenth century, one of its founders made obsessive transcriptions of the ancient carvings on stones throughout the country to come up with a specifically Basque typography. Partly through association and memory, partly through the emotional triggers and resonances it brings, a typeface expresses an endless range of characteristics, even wider in its scope than handwriting. But while it takes a graphologist to decode individual signatures, typographic design can communicate on a conscious or unconscious level with everybody, whether aware of the vocabulary of type or not. Send an email in capital letters, and you know that you have raised your voice to shout. (Sudjic 2008, 37-8)

Sudjic later mentions the graphic designer, Otl Aicher, who believed that if Germany had not been so keen on the use of capital letters, it might have been less vulnerable to fascism; design can inform as well as influence thinking.

Death is central to our religious and philosophical thinking, the essence of much of our human anxiety and insecurity. Our species has the ability to grasp concepts of the future, and to plan and look forward to events, but at those moments in our life when we must face death, we are generally unprepared and feel uncomfortable about the conversations that we need to have, ill-equipped without religious frameworks to comfort and provide answers. Design cannot provide *solutions* to this, but it can serve to communicate and yield substance and connectedness. The limitary nature of the design brief, inspires us to look at problems and distinguish new opportunities and relationships, beyond the form and function and aesthetic of objects, brands and experiences. It can give us courage to see death as being something we can learn from rather than fear, and recognition of this can simultaneously both liberate and ground us.

In his essay, *That to Study Philosophy is to Learn to Die*, the French Renaissance writer Michel de Montaigne examined our relationship with dying and suggested that if we do not fear death we are able to take risks, and without such constraints to limit us, society and individuals can advance socially, medically and technologically.

> Where death waits for us is uncertain; let us look for him everywhere. The premeditation of death is the premeditation of liberty; he who has learned to die has unlearned to serve. There is nothing evil in life for him who rightly comprehends that the privation of life is no evil: to know, how to die delivers us from all subjection and constraint. (Montaigne 1580)

In the context of death, rites and rituals are essential for society; certain things need to happen following a death, a hierarchy of events, practical, ritualistic and symbolic considerations. This common purpose unites the society and provides solidarity to a group in times of grief and mourning. This process cannot really "help" the dead but can be beneficial to the living. For our ancestors in the Middle Ages there was a sense of resignation to death; it was visible and ritualized by society and church, with an unquestioning acceptance that death would lead to an eternal life. Part of the Christian narrative focuses upon death and suffering, with a huge array of spectacularly gruesome deaths of martyrs, burning, wheels, crucifixion, beheading, and mutilation. Our daily death, however, is "other" and distant; murder, war, collateral damage, genocide and natural disasters are consigned to newsfeeds through screens or in print. Death fills our TV entertainment schedules in works of fiction. Death is still the greatest mystery and a source of great narrative content.

Nowadays, we can go through life without ever seeing a dead body. Death has become medicalised and professionalized, the domestic rituals have been lost and the dead and dying are taken to hospitals, where doctors, whose job it is to preserve life, care for the dying. We view death as unnatural, a pollutant and without a religious context, we have no guidance as to how to deal with it or contemplate the possibility of an afterlife. We are obsessed with delaying ageing and avoiding discussions about our mortality. We are often too late to prepare for a good death.

Moth is interested in the formal visual graphic conventions of death (such as the Victorian legacy) as well as the ways in which we might challenge such conventions in order to understand more contemporary attitudes to death and mourning. We are interested in the aesthetics of death, the educational implications and the potential to collaborate with new partners in the visual arts, science and humanities.

In a remarkable project at Raymond Poincaré Hospital in Garches, France, doctors commissioned designers and musicians to create an extraordinary morgue, a space in which the bereaved could see their loved ones for the last time in a considered environment of calm reflection. Musicians David Lang and the British artist Scanner, created two musical soundscapes whilst the physical space was designed by the Italian artist, Ettore Spalletti. Lang's composition, *DEPART* comprised of a meditation on death. This was deliberately written so that it could not be performed live, with a series of unending vocal parts performed without spaces for breath.

With *Moth*, we hoped to discover, explore, question and reveal responses to death through the design process and by creating a series of briefs and workshops, which explored aspects of visual language and typographic opportunities associated with death; mortality, legacy, bereavement and vanitas. This body of work has begun to distil and direct the aspirations of *Moth*, as well as generate more questions and opportunities for the role that graphic design can play in the "Design of Death".

Moth Workshop 1: The Cabinet of Curiosity

In this first project we built upon the legacy of "The Cabinet" as a portal, where objects were placed out of context and served as devices for creating narrative. The popularity of the "Cabinet of Curiosity" (the Wunderkammer—or Cabinet of Wonders) reached its height in the seventeenth century. They were usually personal collections, of natural and man-made objects, which inspired wonder and a sense of curiosity, their system of organisation and classification being idiosyncratic and specific to the individual. These collectors were often gentlemen of means, who wanted to discover, possess and define these objects in order to validate their own intellectual authority and worldliness as well as register their personal interests in the scientific, magical, philosophical and religious potential that the objects possessed.

> The collector was never far from the realm of necromancy, engaged as he was in bringing the dead back to life or consigning living things to death. The funeral connotations of so many of the items central to the cult of curiosities—from mummified limbs to coral branches, from the mythical congealed blood of the Medusa to stuffed animals, from skulls to a charnel house of other bones—were ultimately not only the most superficial expression of this theme, but also the most morbidly fascinating. This dialectic between life and death, this infatuation with the aesthetic transfiguration wrought by death, recurs at an even deeper level, informing the very organisation of the collection. It is central indeed to the thesis underlying the Cabinet of Curiosities: for the aim of any collection is to halt the passage of time, to freeze the ineluctable progress of life or history, and to replace it with the fragmented, controllable, circular time frame established by a finite series of objects that can be collected in full. (Mauries 2002, 119)

Graphic designers are notorious collectors, archiving material ready to use when appropriate; to some folk, it can look like clutter. We think of it as collections of visual flotsam that will come in handy one day, equivalent to tins of screws, buttons and off cuts in the shed. Graphic designers are liberated by the non-permanence of their work, the transient nature of a magazine, poster, and package—yet they have, on the whole, an inability to actually throw anything away. Squirreled ephemera, meticulously alphabetized.

The initial brief of the *Moth* project prompted our graphic students to respond not in visual terms, but with a written piece of work. Designers are visual thinkers but their work requires them to handle large quantities of text as well as edit, write briefs and presentations. They need to be as competent, creative and confident with the written word as they are with the visual word.

> Graphic Designers are the ultimate self-improvers. Each new job and client demands empathy and introduces one to new territories with potential for learning. Words are no more frightening than pictures if one understands the language, and it is the language of words that graphic designers are now called upon to learn. (Roberts 2000, 81)

The cabinet of curiosity also provides and reflects other essential educational skills to design students; curiosity, humour, breadth of interests, ambition, the love of language and craft, reading and writing, systems, arrangement and hierarchy, communication, narrative, responsibility and relevance. Our physical cabinet hosted a series of nine objects over nine weeks and written responses were submitted digitally, many anonymously. The theme of death was not revealed until the project's conclusion at the final workshop. Some students decoded the signs and this in turn began to influence their writing. Unsurprisingly, some students were initially uncomfortable with talking about death, most having had no direct personal experience with dealing with loss or bereavement.

Fig. 14-1 Cabinet of Curiosity: Metaphors of Death

1. Memory & Recollection—Extinguished Birthday Candles
2. A Good Death—A Poison Bottle and a Cigarette
3. The Soul, Shells
4. Regret, a Fetus
5. The Afterlife, Chinese Paper Shoes & Watch
6. Collective Grief, the Poppy
7. Amulet, a Motorist's Prayer
8. Resurrection & Rebirth, a Pomegranate
9. Ghosts, child "Glow-in-the-Dark" Ghost

At this workshop participants were invited to bring objects, which held a personal legacy, having been passed onto them from a loved one. None of the objects chosen had monetary value, but each had a new meaning and subsequent narrative as a result of the relationship. The objects were no longer simply bottle openers, quilts or shoes, they represented people and lives loved and lost. This was not simply about collecting but recognising objects, as portals for the past, legacies for the future and triggers for creative thinking and problem solving.

Moth Workshop 2: Sacred Type

Starting with a typographical field trip to Falmouth cemetery along with examples from our own archive of collected photographic reference, we asked students to embrace the eclectic nature of lettering found on monumental headstones and capture the sentiment of their irregular and vernacular charm. In response, they highlighted the use of; large and small caps with lower-case styles, the random use of italics, arrangement and hierarchy of information, ligatures, incorrect or archaic spelling of words, fleurons used within individual letterforms, the unusual mix of fonts, irregular word and letter spacing and type subjected to wear and damage. Then, using examples of common memorial tributes, we constructed typographic pieces:

> Her end was peace…in loving memory of...beloved wife of...also of his wife…beloved and only son…who fell asleep…gone but not forgotten…who departed this life…in affectionate remembrance of…peace perfect peace…the spot where she lay.

Fig. 14-2 Monumental Stone Cornwall

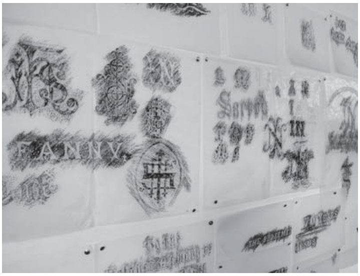

Fig. 14-3 Undead Type Workshop

Fig. 14-4 Undead Type Workshop

As Figure 14-2 suggests, few gravestones exemplify refined letterforms or a sense of an overall design proposal, yet the personal judgment and technical/practical skill of the mason show intuitive genius at work. This awkward hierarchy and idiosyncratic visual aesthetic offers charm and quirks and considerable potential to positively impact on our modern graphic sensibilities and typographical richness. We also looked at the work of Robert Brownjohn and Ed Fella, designers of the 1960s who utilized the visual language of the street as new typographic opportunities and embraced experimental design thinking. In his photo-essay, "Street Level", (published in *Typographica* magazine, 1961), Brownjohn photographically documented the type in the city. This reference celebrated the misspelt, the worn and eroded, poorly spaced and misaligned type, letterforms distorted by weather, reflection and neglect. Earlier, in 1950s France, the artist and documentarist Jacques Villeglé, used the phrase "affiches lacérées" (torn posters) to describe his work, essentially posters torn down from the walls of Paris. He was fascinated by the process of plenty being reduced to the fragmentary transience of decay, by random forces using disparate materials and techniques to "create" works. The same vernacular and visual sentiment can also be said of some of the monumental stones in Falmouth cemetery. Here too, are stylistic variations of ligatures, letterforms, abbreviations, errors and alignment. There are many beautifully carved letterforms, which demonstrate skillful flourishes of the carver's joy of the nature of the material. Some stones have cut or punched metal characters and this lettering is of equal interest and diversity. The gravestones, "read" beyond typographic and aesthetic frameworks, providing us with amorphous narratives which help us to appreciate our present, the cemetery and its stones being artistic and symbolic reminders of the inevitability of death.

Moth Workshop 3: Undead Type

As a follow-up to "Sacred Type", the "Undead Type" workshop considered lettering in terms of typographic anthropology; the creation of a typeface based on individual monumental characters to reflect and respond to contemporary attitudes towards death. It introduced historical context and concepts of death in order to generate discussions and share experiences focusing on ideas and beliefs surrounding what happens at the end of life; the moment at which we die. In terms of the hierarchical design process, this brief prioritized the importance of the emotional response as a source for the rationale of design, over that of concerns about aesthetics, form, functional or legibility.

We initiated conversations about attitudes towards ageing and significant moments within life when we effectively terminate/cease to practise or perform specific functions or behaviours. These moments of loss or change or simply transition, are an inevitable part of life and death.

> Death is not just happening later and taking longer, it is also fragmenting. There are different types of death occurring in the same person at different rates and to different extents in different people. There is death at different levels: molecular death, cell death and organ death, death of the individual, death of the culture and death of the species. There are multiple deaths in different parts of our body and mind: death of our physical abilities and appearance, death of our various mental capacities. There is reproductive death, social death and psychological death. There is death of desire, there is death of memory, and there is death of the will to live. All these things fade away at different ages, at different rates and to different extents. Death is no longer a unified event. It is shattered into multiple uncoordinated processes. (Brown 2002, 8)

The typographic responses included the typeface *Blossom*, which focused on the beautiful fragmentary moments when life becomes crystal clear and beauty is magnified in the face of death. The designers were inspired by the Channel 4 broadcast of the last interview with Dennis Potter by Melvyn Bragg, on March 15, 1994. Potter died on the 7th of June 1994 (just eleven weeks later).

> Below my window…the blossom is out in full now. It's a plum tree, it looks like apple blossom, but it's white, and looking at it, instead of saying, "oh, that's nice blossom", looking at it through the window when I'm writing, I see it is the whitest, frothiest, blossomest blossom that there could ever be…the fact is that you see the present tense, boy do you see it! And boy, can you celebrate it. (Potter 1994, 4-5)

Here, Potter describes the exquisite newness of everything as though seeing it for the first or last time. *Blossom* focuses on fragmented typographic detailing in which the aesthetic essence of the character can be identified and read with minimal elements, and with particular attention to the terminals of characters.

During the workshop, one group discussed the journey of life and the inevitability and abruptness of death. With florid strokes each character had movement and elegance starting at the point of construction and then ending with a solid black slab to define the finiteness of existence, the solid and immovable end, abrupt and unforgiving. The typeface *Limbo* asked the awkward questions that surround death and life, *what do you* *believe in, ascension into heaven, or plunging into damnation?* The descenders, ascenders and shifting x-height carry the message of an awkward conversation, illustrating the direction of our journey into the next life, when death comes to call. The counters and titles give the sense of the earth and a life cycle, intentionally colourless and left blank referencing how we choose to fill our lives before we die. This was a fluid type, changing according to individual choices and beliefs.

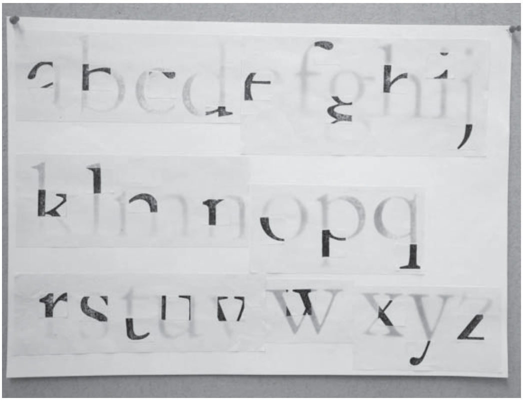

Fig. 14-5 Undead Type Workshop. Work in Progress, *Blossom Type*

Fig. 14-6 Undead Type Workshop

Moth Workshop 4: Memento Mori

"Memento Mori", a collaborative project with Lucy Willow, artist and fine art lecturer (Falmouth University) and twenty fine art and graphic design students, questioned the ideology of "Deathists" vs. "Immortalists". How might we contemplate our own future as being either finite or immortal: an endless hope or a hopeless end? For some, we either simply cease to be, for others we can live forever, through a spiritual, genetic or cultural legacy. We looked initially at the conventions of the *Vanitas* painting and its symbolic reminders that we will die: Man's mortality (depicted by the human skull and bones), symbols of knowledge, arts and sciences (books, maps, and musical instruments), wealth and power (purses, jewellery, gold objects, swords, shells (rare collectors' items)), earthly pleasures of the senses (goblets, pipes, playing cards), symbols of transience (chronometers, burning candles, smoke, soap bubbles, fruit, flowers and butterflies), peeled lemon and seafood, which is attractive to look at but like life can be bitter to taste; and symbols of resurrection and eternal life (ears of corn or sprigs of ivy).

Both Darwin and Freud believed that there were three certainties for man; that he was an animal, that he either learnt to adapt to his environment or else perished, and that death was a conclusive end. For these thinkers, nature, whilst bountiful and fertile was nevertheless transient. Darwinism suggested that it was impossible to reconcile the notion that humans had any special exception from mortality as species are not fixed or everlasting. Darwin was concerned that the growing interest in spiritualism in the mid-1800s would delay thinking concerned with scientific materialism. Henry Sedgwick, a founder of psychical research, spent much of his life looking for evidence, conclusive scientific proof of human immortality: without it, he believed, there was no need to live a moral life and mortal man and his society would therefore be reduced to chaos. During the same period, the so-called "God Builders" of the Bolshevik Russian intelligentsia, believed that science would be able to give them the answers to resurrect and cheat death. With this goal in mind, under the leadership of Leonid Krasin, *The Immortalization Commission* set about to preserve the remains of Lenin. This orthodox belief focused upon the preserved bodies of saints as incorruptible. From this view, Lenin was no less than a saint waiting for such time when he could be resurrected. The constructivist architect, Alexey Viktorovich Shchusev, was commissioned to design a magnificent mausoleum—he used cubed forms in the design, in order to construct a fourth dimension—where death could not exist.

Death and suffering are some of the central themes of Christianity, suggesting that we can gain immortality through embracing death. Christian discourse suggests that although man became sinful and mortal upon his fall from grace in the Garden of Eden, Jesus provides the possibility of regaining immortality in a spiritual form. Immortality also exists via our genetic survival and our investment in cultural symbols or practices, “memes”, to be passed on. These ideas mutate and self-replicate much like our genes to ensure a lasting if not diluted legacy.

The work from the *Memento Mori* project was exhibited at The Falmouth Art Gallery in 2013 and it embraced themes such as; life expectancy and decline; death within life, legacy, death and social media platforms, the abject, of liminality, disintegration, renewal and censorship. In the exhibit, *Tools to Face Grief* (Fig. 14-7), a cabinet contained artefacts and objects which were essentially rejects and fragments. The strangeness and ephemerality of many of these objects, however, paradoxically ensured their reality and value offering living proof that they were once part of something whole, meaningful and real. The work suggested our desire (albeit irrational) to look for personal messages from and to our bereaved loved ones (for example, by cloud watching, star gazing, amulets and prayers) or signs of their comfort in the afterlife.

As demonstrated by these examples, these workshops opened up a range of potential directions for *Moth* and confirmed our belief in the role that graphic design can play in our understanding and relationship with death. The *Moth Projects* create designs that are both mindful and respectful of conventions but which aspire to create contemporary relevant and meaningful understandings of death. As graphic design is a discipline that constantly evolves in order to accommodate changes in culture, society and technology, it is well placed to embrace difficult questions about mortality, aid understanding and provide relevant visual signifiers in the context of death.

Fig. 14-7 *Tools to Face Grief*

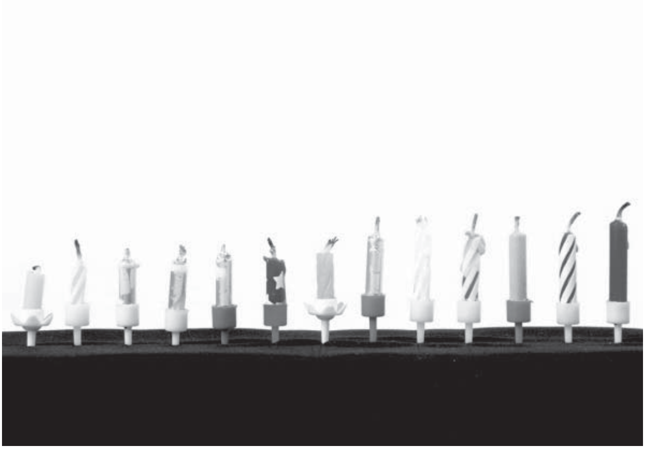

Fig. 14-8 The Light of One Lifetime Extinguished in a Single Breath

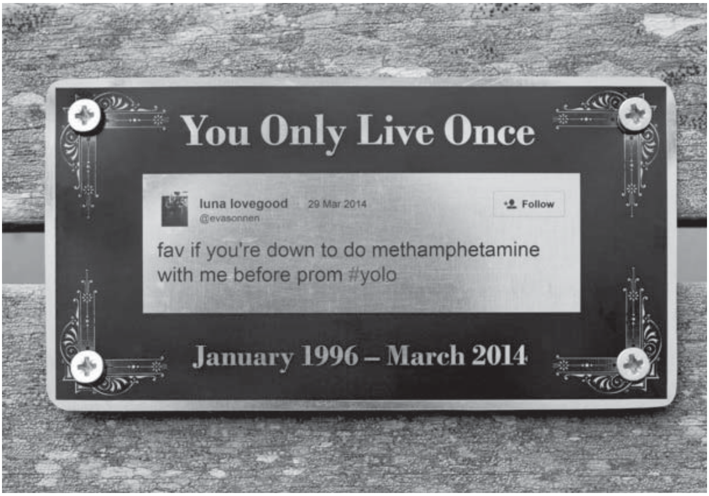

Fig. 14-9 #Yolo’ (You Only Live Once)

Fig. 14-10 Encompassed Death Complimenting Life

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CHAPTER FIFTEEN

GRIEF, ILLNESS AND DEATH IN CONTEMPORARY PHOTOGRAPHY

MONTSE MORCATE AND REBECA PARDO

During the last forty years there have been a number of interesting developments in the ways in which terminal illness and mortality are visually represented and in the use of art to accompany and facilitate the grieving process. Illness and death have become increasingly present in contemporary art, indicating not only that our attitude towards death and grief is changing but also that we believe in the importance of making these visible through art. In recent decades, much has been written about the grieving process in professional and scientific quarters, but the grievers themselves have also addressed their experience and their intention appears to be to normalize the emotional and psychological response of the bereaved person during his or her grieving process (Neimeyer 2007, Parkes and Prigerson 2010, Worden 2010). In general terms, the research on art therapy in grieving processes is fairly extensive but little has been said about the particular importance of art photography and of the photo projects that often deal in intimate and intense ways with the artist's grief. Above all, such projects explore the nature of this grief and the qualities within it that can also help grievers overcome bereavement. This, we propose, should be examined in more depth, especially when the bereaved person is an artist and decides to deal with personal grief by creating art.

Fig. 15.1
Duelos. Serie 1: ¿Por qué? (Grief. Series 1: Why?)

The diagnosis of a close family member's terminal illness is frequently a motivation for art photographers—and sometimes also for ill people themselves—to produce self-referential works of art. Although these narratives preserve the memory and identity of the ill person, the photographer is usually a minor character. For this reason, while photographic projects on the subject of grieving can be considered self-referential (i.e. wherein a person refers to him or herself) not all are necessarily autobiographical (i.e. a narration of a person's life). This is the case of Alejandro Kirchuk's prizewinning project on the subject of his grandparents during the period in which his grandmother suffered Alzheimer's disease, *La Noche Que Me Quieras*, or *Never Let You Go*, which won first prize in the category "Daily Life" in World Press Photo's 2012 event. Kirchuk's project is self-referential without being autobiographical because he documents his relatives' experience without appearing in the pictures himself. On the other hand, Jo Spence's document of her own process with cancer, mainly in self-portraits, is a clear example of a self-referential work that is also autobiographical. In both examples, however, the photographs express intensely emotional content that reaches out to the observer by dint of what Marianne Hirsch has called the “affiliative look”, meaning that our response involves us in a family image that may initially be alien to us but that we adapt to our own family story (Hirsch 2002, 93).

Along similar lines, Rebeca Pardo (2012, 145) uses the term “empathic memory” to describe another process associated with the affiliative look, thus implying a peculiar kind of emotional post-memory (imaginative, creative rather than recollective) assimilated from somebody else’s family memories through their pictures and the affiliative look.[1]

All photographic art projects that deal with personal grief reflect, in one way or another, the particularities and idiosyncrasies of the personal story and of bereavement. For that reason we use the term “grief project” (Morcate 2014) because grief becomes the leitmotif, over and above the malady or death the project might be portraying. And in most grief projects, as we will now consider, the photographer is driven to artistically approach that grief in three basic ways.

Fig. 15.2
Detail of ‘Vitrinas Familiares: Mis Abuelos’
(‘Family Legacies: My Grandparents’)

Firstly, the artist's most visible motivation is the need to pay homage to the subject of the project, the loved one. Whether this person is still immersed in the process of dying or has already died, the photographer uses his or her artistic skills to create a piece of art narrating a very personal story. Secondly, there is the photographer's need to make his or her own grief recognizable to us, the observers. Directly or indirectly, many of the projects say as much about the photographer's relationship with the ill person as they do about that person, and clearly reflect the photographer's own suffering. This intense presence can even become physical, for example, when the photographer's hand is in the frame of the picture, resting on the subject, or when he or she is almost palpable via the look in the subject's eyes. Such occasions reveal the degree of intimacy between the ill person and the camera and, by extension, between that person and the photographer. This is a particularly important part of many grief projects: the photographer attempts to redress the observer's lack of awareness that he or she may also be a griever. The fact is, many individuals go through a grieving process without this ever being acknowledged by their relatives or the people who know them and this can compound and complicate their grief. This often happens when the relationship between the griever and the loved one has not been publicly recognized, or when a person's grief is so intense that others consider it to be somehow inappropriate or abnormal. We might refer to this grieving process as "disenfranchised" (Doka 1989).

After paying homage to the subject and also making his or her grief recognizable to the observer, the photographer's third concern is related to how s/he uses the camera. In the grief project, the camera becomes both protective and mediating, a physical and metaphorical shield but also a device that allows the photographer to face malady and suffering and, ultimately, death. Many photographers have said they use the camera to look straight at what is happening in the moment it happens and at events that would be too hard to contemplate with the naked eye. The camera photographs this new reality, usually in a manner that is harsh and leaves out nothing, however upsetting some of us might find it. To avoid such a reaction, we have to put ourselves in the artist's position as an individual involved in a dynamic process in which the everyday is profoundly transformed, and in which illness and death have become that person's daily environment.

The pictures in this environment portray the loved one in harrowing circumstances, surrounded by doctors or nursing staff and the medical paraphernalia that reinforce the medicalization of death and dying, from oxygen masks to hypodermic needles, the patient constantly portrayed in the process of receiving treatment, often naked. In *Fotografío Para Recordar* (*I Photograph to Remember*, 1991-2007), for example, Pedro Meyer portrays his parents' decline in pictures where they appear extremely vulnerable, photographed in the intimacy of a bathroom or some other place the observer would not usually be invited to enter. These pictures illustrate not only the terminal illness or gradual death of their subjects but also the experience of the person behind the camera, who becomes the silent witness of it all. Besides, during the artist's grieving process, the camera acquires another fundamental function, becoming a means of communication with the loved one. Photo projects like Briony Campbell's *The Dad Project* (2009) or Eugene Richards' *Exploding into Life* (1986) prove that the camera can become a genuine refuge for the photographer and a tool to communicate with the dying person, especially when spoken communication is no longer possible. As Campbell herself declares: "This is my attempt to say goodbye to my father with the help of my camera".[2] Thus, certain pictures take the place of the words that cannot be spoken, helping the grievers to go on being there and allowing them to more actively perform their caregiver-come-companion role in a way that is useful for the artists, especially during the long periods spent in hospital.

As described above, the sort of illness that frequently provides the impetus for the grief project is the terminal or chronic disease, usually a disease that carries social stigma (Sontag 2003). A broad analysis shows that the most frequently documented diseases are cancer (chiefly breast cancer), dementia (forms of senile dementia like Alzheimer's disease, but also schizophrenia) and AIDS. Self-referential projects documenting breast cancer include Ana Casas Broda's study of her grandmother in *Album* (2000) whilst *Narratives of Dis-ease: Exiled* (1990) and images such as "The Property of Jo Spence?" (1982) by Jo Spence present examples of autobiographical projects.

Autobiographical photo-projects about dementia include the work of the schizophrenic David Nebreda, whose self-harm photographs have been classified as a kind of "bodily modification" (Jones 2010), and the mobile photography project that takes as its subject the Catalan politician and sufferer of Alzheimer's disease, Pasqual Maragall (published in book form, 2012). Other self-referential works dealing with Alzheimer's disease or senile dementia include Alejandro Kirchuk's *Never Let You Go* and Julie Winokur and Ed Kashi's *The Sandwich Generation* (2006), a photo-journal which narrates the couple's story of 24-hour home care for their children and Winokur's father who suffered from senile dementia.[3] Other artists have taken more collective approaches to malady, mortality and grief. The photographs of Nan Goldin, that reflected the context of those of her friends that were dying in the 1990s from one of the most stigma-ridden diseases of recent history are probably the most famous.

In most cases, the provision of 24-hour primary care changes an artist's life and the pain witnessed and experienced can thus be transformed into art. This is what Tatsumi Orimoto does in *Art Mama*, having realized one day that "this, my daily life, is art" and that "the existence of my Mama is art" (Wood 2001). *Art Mama* ties together an interesting combination of the themes of kinship, sickness and self-referentiality in family pictures in which the son's relationship with "the other" (his mother) disintegrates because Alzheimer's disease has made her a kind of absentee. In some ways, however, the art project itself becomes a form of shared communication.

Most of the projects described here were completed during the terminal illness of either the subjects or the artists themselves. However, many other projects dealing with illness, mortality and grief only start when the subject's physical death has already taken place. Completed on very different terms, these projects generally involve photographers dealing with their grief by using art to pay homage to the dead and as a means of prompting themselves, often in very intense ways, not to forget. There is also considerable variety in the ways these photo-projects approach grief: Belinda Whiting's *Sophie's Story* for example (published in book form, 2012) includes a series of decontextualized old family photographs; Miyako Ishiuchi's *Mother's* (a series completed during the period 2000-2005) recalls the loved one by portraying her personal belongings; Rebeca Pardo works with the memory of her grandmother's Alzheimer's in *Family Legacies* (2011); and in Montse Morcate's *Duelos (Grief)* (2011-2013), a funeral bouquet substitutes the tangible void left behind by the loved one's death.

Conclusions

Our analysis of photographic projects produced during the time a subject was dying or soon after the subject's death confirms that artistic works can play an important role in overcoming grief. The camera becomes the key element in the photographer's attempt to face an intense and private situation. Through it, the photographer transforms a sensation of powerlessness into a sense of control and feels that s/he can do something important and useful by capturing what is taking place. Photography becomes the means by which the memory and legacy of loved ones and relatives can be conserved.

These new photographic practices are changing contemporary representations of intimacy. In photo-projects such as these, professional photographers represent daily life without attempting to imbue it with what we might call classic "beauty". These images approach the "abject" and cross the borders of what can or cannot be represented and how representation takes place. By focusing upon the pain and suffering of the photographer and the subject, these photographs question the taboos of the traditional family album, recording end-of-life situations within hospital environments and/or at the mercy of medical treatment. The new visual context generated by social networks is especially important here but these projects also raise awareness of the frequently neglected needs of families whose problems are invisible to many or who risk social exclusion because of the stigma their illness carries. In this sense, photo-projects such as the ones discussed in this chapter also expose the shortcomings of our welfare state and society in general, revealing our reluctance or lack of preparation to take care of those who suffer from incurable diseases and our refusal to acknowledge the limitations of medicine or accept death itself.

Finally, as most of these art projects begin as instinctive responses to new and difficult situations, the camera becomes both a shield and medium of communication with the dying subject. Furthermore, whilst most of these photo-projects are exhibited after the death of their subjects, for the bereaved, they function as tributes to those who are no longer here and signal a final step in a long grieving process.

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Notes

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[1] Marianne Hirsch considers that "post-memory" is distinguished from memory: "Precisely because its connection to its object or source is mediated not through recollection but through an imaginative investment and creation" (Hirsch 2002, 22).

[2] Briony Campbell's declaration in the video "Saying Goodbye with a Camera". Accessed 06.02.2014. Available at:
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[3] It is also worth noticing the importance of Alzheimer's in recent years in Spanish documentary films with two self-referential films from the same year and city (2008, Barcelona) which study the same historical period (they examine people's memories of the Spanish Civil War, the post-war years and the dictatorship in Spain). This coincidence is important because both films deal with the representation of illness and the problem of stigmatization or of the ill person's neglect by the authorities. On the other hand, some self-referential documentaries about Alzheimer's use the memory of a family member's "illness" to investigate that past. In cases where the relative lived through politically difficult times, the camera can provide a means of recalling memories through the personal, familial gaze of a son or a grandson whose research, at another level, appears to be "just about a relative". This seems to be an easier way of negotiating painful memories from complex political contexts.

CHAPTER SIXTEEN

IMAG(IN)ING THE DEAD AS ANGELS[1]

TONY WALTER

"Rest in peace dear daddy, I love you...
I am so proud to have you as my guardian angel"
(Online tribute)

"Lost a Friend, Gained an Angel"
(On t-shirt of mourner for British soldier killed in Afghanistan)

"Shopping with Angels"
(Memorial bench carving)

In the twentieth century, the most popular afterlife belief in Northwest Europe and North America was that the soul goes to heaven where it is re-united with other deceased family members; in the twenty-first century, however, the dead are increasingly described, especially online and by younger mourners, not as souls but as angels. In two other publications I analyse this development in terms of religion and bereavement (Walter 2011, 2016); in this chapter, I examine the image of the angelic dead as a literary and visual accomplishment.

My articles argue as follows. In the mid-twentieth century, before divorce rates escalated, increased longevity produced unprecedentedly long marriages which, combined with romantic ideals of love, produced elderly widows who found comfort in the thought that soon their soul would join their husband's in heaven. After a long life of hard work, people could look forward to a quiet, peaceful existence with their beloved, both in old age and after death (Walter 1996). Younger mourners today, however, face a different prospect. Children or young adults mourning a grandparent, sibling, child or friend can expect to continue living on earth for fifty, sixty or seventy more years; that is a long time to be separated from the deceased, and in the meantime a consumerist post-industrial lifestyle eschewing delayed gratification awaits enjoyment. To such mourners, delayed soul re-union holds little attraction. Souls locked up in heaven (Quartier 2011), inaccessible until the younger mourner him or herself eventually dies, may perhaps articulate a modernist, Freudian notion of divesting personal attachments to the deceased (Freud 1984), but are less attractive to the more romantic—and enduringly popular—concept of a continuing bond in which the living move on with, not without, the dead (Klass et al. 1996). So in comes the idea of the deceased as an angel—with wings and hands and agency, not least agency to guide the living—articulating an ongoing bond between the dead and living mourners who still have many years of active life ahead and who wish the deceased's memory and values to be part of that life. The angelic dead thus comprise a vernacular religious "meme" providing comfort to younger mourners today. Given that formal religions, contemporary "spiritual" books and late twentieth-century movies all teach that angels were never human, the angelic dead comprise a genuinely vernacular, "bottom up" idea, a resource mourners have created for themselves and spread, virally, online.

How, though, is this image of the dead accomplished through text and visual imagery? That is the subject of this chapter. I will first sketch the history of representing the dead as angels, before examining their representation as angels today, first visually and then textually.

A Brief History

In formal Christian, Jewish and Islamic doctrine, angels are a completely different order of being from humans; they never were human. The popular idea that deceased children become angels, however, goes back in Western Europe at least to the late Middle Ages, and in German folklore, deceased children have been described as "beautiful little angels" for many years (Hoffmann-Krayer and Bächtold-Stäubli 1987). In Hans Christian Andersen's tale *The Angel* (1844), a child dies and becomes an angel who carries other deceased children to heaven. There are also occasional literary examples of adults becoming angels; in Shakespeare's *Hamlet*, for example, Laertes calls his departed sister Ophelia "a ministering angel".[2]

Appearances of once-human angels likewise go back many hundreds of years in European visual culture. The figure of the putto and its relationship to angels and cherubs is ambiguous, but in the Renaissance and especially the Baroque it became fashionable to picture heavenly winged beings as babies (Dempsey 2001; Jones 2011) and, exceptionally in Poland, explicitly to picture deceased babies as winged putti (Labno 2011). This is echoed in internet infant memorials today (Keane 2009). Winged cherubs are found on many eighteenth-century tombstones—possibly as the souls of the dead taking flight or as angels guiding them to heaven. The ambiguity is perhaps intentional, allowing visitors to find comfort in their own different ways (Garrett 2008, 186). This ambiguous image is often found in New England gravestones: “European cherubim were transformed into soul effigies by the stonecarvers of New England and it is often difficult to tell created angels from glorified souls”. (Ludwig 1966, 14-15). By the nineteenth century, gravestones frequently display more obviously baby angels.[3]

There is also the late seventeenth-century New England tradition of the winged death’s head or skull, dominating the top of the gravestone (Ludwig 1966). By the nineteenth century, most cemeteries on both sides of the Atlantic contain a goodly complement of adult winged angels, typically standing firmly on the ground but again with some ambiguity—are these angels taking the dead to heaven, or has the dead become a guardian angel in order to look after those left behind? (Slivoski n.d.). Two influences were arguably at play here. First, romanticism’s focus on the eternal nature of human love generated a more loving and familial than religiously judgmental view of death and the afterlife, expressed in angels lovingly carrying the dead to heaven (Ariès 1981). Second, Emmanuel Swedenborg, the unorthodox eighteenth-century theologian, taught that the deceased soul does not sleep but leads an active life in heaven and that all angels—including those taking the recently dead to heaven—were once human; Swedenborg influenced American thought and, through memorial sculptor Flaxman, British funerary sculpture. Swedenborgianism peaked in the nineteenth century, but may have left traces in popular afterlife iconography and belief (McDannell and Lang 2001).

Twentieth-century Hollywood’s 1946 movie *It’s a Wonderful Life* stars the angel Clarence, who had lived as a man two centuries previously. But this movie is an exception. Central to the plot of two more recent angel movies is that angels were never human, and indeed yearn for a human body. Here, humans do not (and cannot) become angels, but some angels choose to become human—a journey they cannot reverse. Thus Wim Wenders’ 1987 film, *Wings of Desire*, stars an angel who falls in love with a human and so wishes to become human; and we find in the course of the movie that other angels have previously made this transition, for walking the earth are some humans who were once angels. In *City of Angels*, a 1998 remake of Wenders’ plot, an angel asks his companion, “This little girl asked me if she can become an angel.” His companion angel, Seth (the film’s central character), replies “That’s what they all say. Tell them the truth. Angels aren’t human. We were never human.” The two angels struggle with having too much infinity, with having no physical sensations such as touch. In due course, Seth chooses to fall to earth to *become* human, to have free will, to experience the senses. The film’s assumption that the task of angels, who were never themselves human, is to guide and protect humans is in tune with the angel boom then current in the USA (Gardella 2007).

The idea that all the dead become angels thus comes not from formal teaching, whether Christian or New Age (Utriainen 2015), nor even from movies but from ambiguous elements of (both high and popular) visual culture, not least the visual language of the Victorian cemetery. There is also a more consistent, but still vernacular rather than formal, notion that dead babies become angels. How then does contemporary visual culture turn the dead into angels?

Visual Culture

How to draw a soul? Not easy. Angels, however, may readily be portrayed visually. One reason for the contemporary prevalence of angels may be because contemporary popular culture—particularly digital culture—is so visual. If mourners need to communicate visually, the easiest way to represent a dead person is to photograph or draw a picture of them and add wings—this meaning is readily understood within contemporary visual culture. Person + wings = dead person. Certainly children understand this formula.

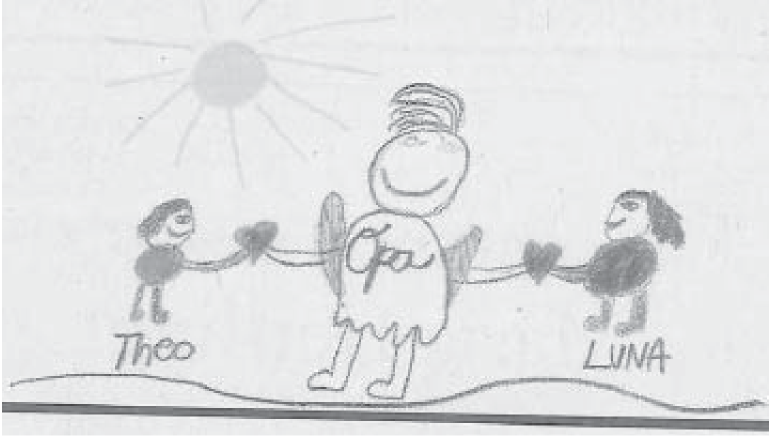

Fig. 16-1 *Trierischer Volksfreund*, 17 December 2013

I will illustrate this with a children's drawing (Fig. 16-1), digitally reproduced within the death notice in a provincial German newspaper to Helmut Lautz who died in December 2013, aged eighty.[4] The drawing is by two of Helmut's grandchildren, Theo and Luna (aged four and eight), and depicts their Opa (Grandad) as a smiling angel with yellow wings matching a bright yellow sun, holding his grandchildren's hands which are transformed into red hearts. Opa's wings are how his grandchildren show that he is dead, yet still in touch with them. This "touch" is no mere mental memory, but an active bond of love expressed through loving hands. The drawing shows an Opa not in the heavenly company of God or of other deceased souls, but an Opa living in his grandchildren's hearts. The yellow sun and smiling face convey positivity. This beautifully and simply expresses what contemporary social scientists mean by "continuing bonds" with the deceased (Klass et al. 1996).

Perhaps more important than Opa's wings are his hands. Whereas his wings signify his deceased status, his hands enable him to exercise agency, to continue caring for his little grandchildren. As poet Jackie Kay puts it:

> The dead don't go till you do, loved ones.
> The dead are still here holding our hands. (Jackie Kay *Darling*)[5]

Indeed, although some paintings of angels give them enormous wings for transporting the recently dead to heaven or for protecting the living, others (like Theo and Luna's) provide them with merely token (and entirely non-aerodynamic) wings and emphasise what their hands can do, whether that be blowing trumpets and playing lyres to the glory of God or caring for the living on earth. Angels' bodily parts have purposes.

Digitally reproduced drawings in newspapers apart, in what other visual contexts are angelic representations of the dead found? The cemetery and memorial, the internet and the online memorial, the tattoo, these are highly visual places—whether material or digital—where the living encounter the dead, and in the case of the tattoo where the dead are literally inscribed on the living. It is therefore not surprising that it is to these places that the dead, as angels, fly. In the cemetery's liminal space, the most common activity by visitors is communication, with the living (affirming family structure as particular graves are visited) and with the dead, whose help and protection is sought (Schmied 2002, Francis et al. 2005). Since angels can communicate with the living more effectively than can souls, and may be more readily represented in stone and plastic, it is not surprising that angels are found on graves. I do not claim that all contemporary graveside representations of angels express, like Theo and Luna's, a continuing relationship of love. The cemetery of a Tyrolean village I visited in 2011 was very actively maintained, with most graves displaying a profusion of adornments. In the nearby flower shop in which many of these "grave goods" may be purchased, I bought a small contemplative angel with the inscription *Es Bleibt die Erinnerung*, "What remains are memories". This angel represents memory, consistent perhaps with a more modernist understanding of letting the dead go, rather than an angel who continues the relationship between the living and the dead—though as an English memorial bench proclaims, "To remember is another way to love".[6]

Physical memorials outside cemeteries can also feature angels. After the 2012 shooting of twenty-seven people, including twenty children, at the Sandy Hook Elementary School, Newtown, CT, a local artist created twenty-seven angels which he hammered into the ground near his home. (The twenty-eighth deceased, the shooter himself, was not represented and did not become an angel.) Following the shooting, an X-Factor star recorded a special rendition of *Angels Among Us*, while online there were many angel tributes. Whether these different media were picking up the angel meme from each other or independently from contemporary culture, is difficult to know.

In the following extract from a study of memorial tattoos, the interconnection between different media is clear.

> Paul's mother died in 2004 and he felt "compelled" to get an angel tattoo in her memory. He then decided to get further tattoos for his uncle and father-in-law by adding a male angel design. Finally, he added blue and pink stars on his collarbones to symbolise all the family members who had passed away, their position reflecting the tattoo his mother was given for her radiotherapy treatment. All of his family members were cremated and so he feels his tattoos are their "headstones" for him to "visit" and "tend". (Sharp 2009, 60)

Internet memorials to the dead are probably now the most common location in which the angelic dead appear, though, as will be seen below, these appearances are currently more textual than visual. The exceptions are memorials to deceased babies and miscarriages which, as Keane (2009) has shown, are replete with baby angels, and indeed many online baby memorial sites have angel in their title. The other dominant image in pre-term memorials is the ultrasound image. Keane argues that these two representations—angel and ultrasound—materialise for the grieving parents the child who never materialised, and thus offer them a person to grieve and with whom to have a relationship. Hughes et al's (2002) study of stillbirth memorial practices raises the question whether this kind of visualisation and materialisation promotes psychological well-being, but that is not the issue here; parents choose this visual memorialisation, whether it carries for them a psychological benefit or a psychological cost.

My previous work argued that the dead become angels for mourners who themselves are relatively young and can expect to live many more decades on this earth. I have come across one significant exception, and that is the picture book, *My Henry*, by the bestselling English children's author, Judith Kerr (2011). The story features an elderly widow in residential care who spends her afternoons dreaming of adventures with her Henry, whose angel wings enable him to take her out of the residential home each afternoon and together they ride dinosaurs, climb Mount Everest, and water ski with dolphins. Given Kerr's own biography, which includes a long companionable marriage and increased productivity as a writer when widowed in her eighties, I read this story autobiographically as an allegory of her ongoing relationship with her deceased husband, their relationship more real than the institution in which the fictional widow currently resides. The story raises the question whether contemporary baby boomers, as they themselves come in due course to confront elderly widowhood and widowerhood, may not be sitting in their cardigans and slippers waiting for their own soul to join the deceased's in heaven, but may be inviting the deceased to join them in the active old age now deemed to comprise healthy ageing. Whether Kerr's story is an exception to my thesis that only younger mourners picture their dead as angels, or prophetic of how a reconstructed old age will lead to reconstructed afterlives, only time will tell.

The Image

To what may depictions of once-human angels be compared? As spiritual beings with physical form, a number of possibilities come to mind. Here I look briefly at three: resurrection bodies, ghosts, and bats.

Over 2000 years, Christian concepts of the afterlife have oscillated between the soul sleeping until the Day of Resurrection when it will be re-clothed with some kind of material body, and a soul that continues immaterially for eternity (McDannell and Lang 2001). In the twentieth century, apart from conservative evangelicals and traditional Catholics who tended to retain belief in a physical resurrection, many Christians came to see the afterlife in terms of an immaterial soul. I have contrasted the dead becoming angels with the concept of the sleeping soul, but is there a sense in which the once-human angel returns us to something more akin to a resurrected body? Like resurrected bodies, represented in sculptural form in a number of European cathedrals, angels may easily be represented visually. Angels may not be material but they are imageable—and one can begin to see how it was that in the Middle Ages St Thomas Aquinas pondered how much space, if any, angels took. The Reformation and the modern era were primarily text-based, but the twenty-first century is arguably a more visual culture, for the first time since the Middle Ages, thus re-creating representational space which angels may inhabit.

Conceptually and linguistically also, angels seem to have less in common with souls than with resurrected bodies. In soul language, we describe ourselves as body and soul—soul is part of the body-and-soul binary. Resurrection theology, however, supposes not a binary but a single concept of the person: we are a whole person, who at death dies, but is then in its entirety miraculously resurrected by God. In this theology, a soul without a body is no person and therefore offers no hope (Cullmann 1958). Angels likewise do not imply a binary notion of the person—we do not say body-and-angel. Are angels more like St Paul's spiritually resurrected body? Or even some kind of spiritual reincarnation? Like resurrected bodies, they are something visual, if not material, which one *becomes*, unlike the soul which one already is/has. St Paul not only taught that Christians will one day be transformed into "spiritual bodies", but he also compared these to stars, which in Hebrew thought often equated to angels; hence it has been argued that St Paul envisaged the end-time transformation of Christians into angels (Segal 2004, 399-440; Garrett 2008, 225).

Visualising the dead as angels may be compared not only with St Paul's resurrected body but also with other images and creatures. The most obvious is the ghost, another immaterial representation of the deceased, but whereas ghosts in western culture are potentially troublesome (Finucane 1996, Davies 2007), today's angels are almost entirely benign. Ghosts were popular among 1990s youth, but contemporary youth culture, not least movie culture, focuses more sharply on vampires, werewolves and zombies, all of which imply connections between the living and the dead. Societies that are rapidly de-Christianising in terms of formal adherence to the church and its teachings, nevertheless are producing a popular culture in which all kinds of creatures are explored by young people in order to make sense of life and death (Coombs 2014). But when it comes to more personally expressing loss or offering condolences, it is the once-human angel that is most in evidence.

Bats are the only mammals that have wings and fly (squirrels glide), but unlike angels who have wings as well as arms, the bat's wings have a bone structure more like human arms than birds' wings.

> This wing structure also helps explain the distinctive manner in which they can wrap themselves in their wings when roosting, as if drawing around a cloak…Our fascination with bats has made them a powerful cultural element—as both good and bad. On the one hand, there is Dracula: a grisly vampire vision that draws on stories of the bat's blood-sucking habits and avoidance of daylight. On the other, there is the continued metamorphosis of the do-gooder caped crusader, Batman. This human-bat creation is a troubled superhero, who constantly uses the bat's strengths to battle the fundamental amorality of nature. (Flach 2012, 172-3)

So why are few, if any, comparisons made between bats and angels? Is it because of the Christian division of light and dark, so that, bats being creatures of the dark, only the devil could be bat-like? In Bradford Cathedral two wall memorials (1710 and 1711) depict a skull enfolded in a bat's wings, suggesting death and decay.[7] Ludwig (1966, 82) discusses a 1776 New England gravestone of the *memento mori* type, featuring in the centre a grisly skeleton, attended by the competing claims of (in the top corners) two angels of heaven and (in the bottom corners) two bats of the underworld. The presence of bats on gravestones was relatively rare, but this example suggests an understanding of bats as the devil's angels. Twentieth-century Batman, by contrast, harks back to the biblical/medieval angel executing justice. And of course, like an angel, he has arms and hands as well as the cloak that doubles as a wing. Contemporary angels, however, are more androgynous or female, offering care and guidance rather than executing justice (Zuffi 2003), and it is these that contemporary western humans imagine their loved ones becoming.

Text

The bereaved have probably talked to the dead since time immemorial. In the twentieth-century West, they typically did so in private, for example at home, at the graveside when nobody else was around, or silently under their breath (Stringer 2008). It seemed something to be mildly ashamed of, or at least embarrassing (Bennett 1987). By the late twentieth century, this practice became more public, for messages written on cards at spontaneous shrines or in condolence books after a celebrity death (Jones 1999, Brennan 2008) were often addressed to the dead. Twenty-first century Facebook posts to the dead take this a step further in that they are posted in the presence of an audience of living friends and peers who, by also addressing the dead online, legitimate the practice (Brubaker and Hayes 2011, Kasket 2012). At the same time, Heaven and the afterlife seem to be making a comeback on social network sites like Facebook, even in quite secular countries such as Germany, Sweden or England. The two phenomena—addressing the dead in the company of others, and the reappearance of heaven—may be connected. Talking to the dead implies that they can be imagined, that they are somewhere and may even be able to receive messages. It is difficult to address somebody without implying they exist. Thus we find on Facebook posts such as "See you in heaven", "Hope you're having fun up there with the angels" (Jakoby and Reiser 2013). It is one thing to share memories online with others who knew the deceased, but to actually address the deceased implies that they exist, somewhere. And if there is a feeling that the deceased can read the message (Kasket 2012), then this implies a degree of agency, which souls traditionally do not have but angels do. Moreover, with social network sites now largely accessed via mobile devices, cyber-heaven is no longer a special place you have to go to by logging in to a static computer. Today's deceased in heaven may be accessed any place, any time; they become part of everyday life. Angels, who also are everywhere all the time, are thus a particularly apt representation of the contemporary online dead.

What we find on sites such as Facebook are textual messages addressing the angelic dead, accompanied by photographs of the dead taken while alive or their favourite music. Facebook is not a site where visual images of once-human angels are to be found, unless it be for a miscarriage or stillbirth for whom no photographs (other than ultrasounds) are available. This textual presence of once-human angels characterises Web 2.0, i.e. user-generated content in interactive sites such as Facebook. Roberts and Vidal's study of earlier, 1990s, web memorials mentions religious themes, especially the continuation of the spirit. Thus one quote (from 1997) refers to the deceased's soul: "May the Lord bless his soul and may we meet again in the next life. God bless his soul!!!!" (Roberts and Vidal 2000, 534). But Roberts and Vidal make no mention of angels. Though angels as everyday guides were popular during the 1990s in the USA and some European countries, it was not until the mid-2000s that the dead became angels in significant numbers, possibly due in part to the conversational affordances of Web 2.0.

How then do textual depictions or addressings of the deceased as an angel work? First, it is important to understand that the once-human angel is not part of any well worked out philosophy or theology, but a meme, a single idea, that mourners draw on within particular communicative media. It is a fluid idea which may be used with considerable ambiguity and it is precisely this ambiguity that enables it to work as a symbol (Walter 2011).

Second, although I have said above that after death one *becomes* an angel, in a number of posts a link is made to the deceased's pre-mortem character. A funeral celebrant emailed me: "My clients often talk of the deceased as a living angel because they were an 'angel' on earth". Thus the charm of a young girl, or the wisdom of a favourite uncle, may qualify them post-mortem to be a bright sunny angel or a helpful guardian angel. But mourners may make connections between post-mortem angelhood and pre-mortem character even for some whose pre-mortem lives were not thought angelic at the time. Thus online commemorations for Jade Goody, a young Englishwoman who became a celebrity not through any charm but through forthright language and brash interpersonal behaviour on the TV reality show *Big Brother*, include (Walter 2011):

> "I hope heaven opens the gates for you, they have gained a selfless angel"
> "God now has a larger than life angel by his side to brighten up heaven"
> "Our giggling angel..no doubt you"ll be looking down on us all and giggling away :) u were such an inspiration jade"

And though angels are not mentioned, the same idea is present in this tribute for singer Amy Winehouse, tied to a tree in Camden Square, London: "Please sing for my grandparents and Pierre in heaven! And have a drink with them too!"

In linking earthly character with heavenly destination, the mundane with the eternal, these (largely online) mourners achieve something that clergy struggle with in funerals (Quartier 2007, Hauenstein 2009, Bridgman 2010, Walter 2011). Christian teaching portrays heaven as a place where the soul's individual personality is significantly reduced (Quartier 2011), but the textual angels found online are identifiably personal, contributing their unique personality to heaven itself. *Visual* depictions of the angelic dead, however, are typically depersonalised, generic, as in baby memorial sites. It is only in text that character is apparent. Even in Theo and Luna's drawing, it is only their and Opa's written names that identify the angel as their granddad. The image itself could be anyone. The only exception I am aware of, where pictures as well as words clearly identify the angelic dead as a unique individual, is *My Henry*, a work of fiction that is professionally illustrated (Kerr 2011). In more vernacular sites, it is text that does the work of maintaining the angelic deceased's unique personality and agency.

Third, the angelic dead signify a new departure in eschatology. For two thousand years, Christian teaching has oscillated between portraying a theocentric heaven in which souls (or resurrected bodies) spend eternity praising God, and an anthropocentric heaven in which souls spend eternity enjoying the company of their own familial dead (McDannell and Lang 2001). But now we see a new development, an angel-centric heaven, in which the dead are portrayed as spending eternity in the company of neither God nor other souls but of angels. The emphasis is often on the dead being with the angels, rather than—or as well as—becoming an angel (Walter 2011). Thus the death from melanoma of a devout forty-year old American Episcopalian was announced on her own blog thus: “Kirstin died a few minutes before 8 p.m. tonight. After a day of many of us singing to her, she is now singing with the angels”.[8] In a more jocular vein, and probably written somewhat longer after the death, the widow of forty-five-year-old Anders wrote on a Swedish memorial website: “All the angels are going to experience your good humour; the winds will spread the sound of angels laughing at your jokes” (Gustavsson 2013, 105). Similarly, a Jade Goody memorial post says, “I imagine you up there making the angels laugh as you have made us laugh.” The dead display their pre-mortem character not only through caring for, guarding and guiding the living, but also in the things they do with the other angels.

The dead becoming angels and the dead in the company of angels need not be entirely distinct; Kirstin and Anders are doing things—singing, laughing—that angels apparently do. A bench at Olney Natural Burial Ground, UK, is inscribed “Shopping with Angels”, leaving it unclear whether the deceased has actually become an angel. Being with the angels is easy to write about, but harder to depict visually—unless the deceased is him/herself depicted as an angel. So the dead being *with* angels is a literary, not a visual, device.

Contemporary mourners have taken centuries-old images of angels, and re-worked them. A glance at the many Renaissance paintings of angels reproduced in Christmas cards reveals two types: the single angel giving a message to Mary; and the angelic host (singing, playing harps and blowing trumpets in praise of God).[9] We find in contemporary mourning both the idea of the deceased as a solo guardian angel looking after the living, and the idea of the deceased joining in the joyous activities of the heavenly host. These activities, however, are now valued for displaying not the greatness of God but the deceased’s earthly character.

Conclusion

In depicting the dead as angels, online mourners shift focus from relationships within heaven among the souls of the familial dead, to relationships between the angelic dead and those left behind on earth and to relationships between the angelic dead and other (non-familial) angels in which the angelic dead continue to display their pre-mortem character. These relationships are readily written about and, though the deceased's character may be hard to represent visually, the very concept of angel is inherently visual. Like ghosts and vampires, but unlike souls, to think "angel" means to visualise angel. But unlike ghosts and vampires, the angelic dead's everyday positivity, captured in Theo and Luna's drawing, gives no hint of the shades and séances in which the gothic imagination has hitherto portrayed contact between the living and the dead. The angelic dead thus provide a positive language and image for articulating continuing bonds between the living and the dead in both secular Europe and still religious North America.

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Notes

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[2] Act V, Sc.1.

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[3] https://www.google.co.uk/search?q=little+angel+tombstone&tbm=isch&tbo=u&source=univ&sa=X&ei=rixAUsPeDsLW0QWF84GoAQ&ved=0CE8QsAQ&biw=1024&bih=642&dpr=1

[4] *Trierischer Volksfreund*, 17 December 2013. Reproduced by permission of Luna and Mattheo’s mother, Alexandra Lautz (Helmut Lautz’s daughter).

[5] http://www.poetrysociety.org.uk/lib/tmp/cmsfiles/File/review/964kay.pdf

[6] Charlcombe Church, Bath.

[7] Monuments to Faith Sharp and John Smythe. http://www.speel.me.uk/sculptplaces/bradfordcath.htm

[8] http://barefootandlaughing.blogspot.com/ Post for 1 July 2011.

[9] I thank Malcolm Johnson for this observation.

CHAPTER SEVENTEEN

DEATH IN ENVIRONMENTAL ART: SELF-ERADICATION TO MASS MORTALITY

ALEX MURDIN

> One of the penalties of an ecological education is that one lives alone in a world of wounds...An ecologist must either harden his shell and make believe that the consequences of science are none of his business, or he must be the doctor who sees the marks of death in a community that believes itself well and does not want to be told otherwise. (Leopold and Leopold 1966, 197)

Death has always been at the core of environmentalist thinking as one of its foundational precepts. In ecological terms it is largely discussed in relation either to the death of the planet, and our co-species, or in terms of the potential for the mass mortality of human populations both imminently and at some future point. One regularly used indicator of environmental crisis is extinction rate, which is in the process of rising; the current extinction event is the sixth largest known in geological records. Equally, as human global population reaches levels above 6 billion, pressures on resources, environmental degradation and climate change are believed to threaten food security with consequent famine, war and disease (Zalasiewicz et al. 2010). In recognition of these threats, new environmental sciences have fed the rise of “sustainability” politics concerned with averting these futures in some way. In parallel, an environmental art movement has lead at a cultural level in developing aesthetic responses to this crisis. However, addressing the ever-present implication of death at both the level of the individual and at the meta level of populations remains to a large extent culturally taboo, suppressed societally for the same reason that the certainty of death must be inhibited in order for the individual to function in the face of the knowledge of its own certain demise. Those artists that address this subject in their work therefore make an interesting exploration of the cultural blind spot this creates in the vision of the environmental subject.

Awareness of the potential for large scale mortality in environmental terms is nothing new, although not of course framed in terms of its modern meaning. In the eighteenth century the Reverend Thomas Malthus saw an increasing population underpinned by the technological advances of the industrial and agrarian revolutions taking place in the UK which had improved food production. However, in his *Essay on the Principles of Population* (1798), he forecast that "the power of population is indefinitely greater than the power in the earth to produce subsistence for man" (Malthus 1998, 4) and that increases in population would ultimately be the cause of mass suffering, "sickly seasons, epidemics, pestilence, and plague advance in terrific array, and sweep off their thousands and ten thousands" (ibid., 44). This environmental catastrophe would potentially be finished off (as it was caused) by human vice as wars would kill off more in the ensuing struggle for survival. Malthus concludes his essay by saying that the only solutions to this prognosis were a more moral government of the existing social order and trust in the higher power of God. This apocalyptic vision of an unsustainable population on the verge of destruction retains currency although it is reformulated in the language of science as a natural biological/geological force. It is perhaps ironic then that contemporary ecology has seen the re-introduction of a type of New Age divinity in the form of holistic ecological paradigms. The most well-known of these is the influential Gaia theory of James Lovelock which suggests that the life-forms that make up earth are a self-regulating entity. In this ecological world view human tendencies disrupt and destroy this global entity through climate change, pollution and depletion of resources in a way which has been described as pathogenic, that is to say humans are a disease of the planet's body (Bartlett 2006). Philosopher John Gray works through this idea to consider the results:

> Our possible outcomes…destruction of the invading disease organisms; chronic infection; destruction of the host; or symbiosis—a lasting relationship of mutual benefit to the host and invader. (Gray 2002, 8)

Chronic infection is arguably what we are experiencing now, an entrenched disease which causes the planet to limp on but which needs to be addressed. Destruction of the host, the death of the earth, would actually be extremely difficult in absolute physical terms, although perfectly possible if we think of the living systems of earth. As it is argued that failing to treat the disease would lead to the planet's termination this leaves two more positive alternatives, symbiosis between humans and the planet or the destruction of the invading organisms, the human disease. Unsurprisingly, symbiosis is the preferred vision of most, allowing both humanity and the ecology of the earth to co-exist and visions of this future are common amongst environmental artists. Since its origin in the 1960s the environmental art movement has mostly been positivist in this way, with artists using their practice either to raise awareness of impending ecological catastrophes or going as far as making curative ecology part of their artwork, the so-called "ecoventionist" approach (Spaid 2002). Examples are the works of Alan Sonfist like *Time Landscape* (1965) which replanted historic native American species in a New York park, or *Revival Field* (1990) by Mel Chin in which a chain link fence encompasses a small piece of the Pig's Eye landfill site in Minnesota contaminated by heavy metals, within which are placed plants which extract these toxic additives from the soil. More contemporaneously there have been the strategies of socially engaged art practices which aim to foster better ways of living with the planet, like the project *Biogas* (2002) by Superflex in 2002 where they worked to create biogas generators in Thailand to make a more sustainable fuel source for local people.

However, these forms of symbiosis have been problematised by a few artists who explore the presence of death in ecological thinking. One of the originators of the environmental art movement was eco-feminist Ana Mendieta. In 1973, in Mexico, she made the first of her *Siluetas*. These are the imprints of the artist's body formed in mud, earth, marshes and snow. Occasionally she would use red pigments in the imprint to suggest blood, or set fire to the spaces created using gunpowder. The *Siluetas* can be seen as both images of harmony with the earth, of the artist reborn in the earth, but also as images of the individual's death and sacrifice, a burnt offering for a mother.[1] A contemporary of Mendieta's, Nancy Spero, describes her motivation:

> Ana's anger fed her desire to create works of endurance, works made to exorcise—with blood, with fire, with rock, with earth, with stress—her profound sense of displacement. Her art is an elemental force, divorced from accidents of individuality, speaking of life and death, growth and decay, fragility, yet indomitable will. (Spero 1992)

These works therefore suggest a process of redemptive self-destruction in favour of an eternal nature: in John Gray's schema this is the only alternative to symbiosis that remains within the scope of human agency, self-destruction or "destruction of the invading disease organisms" (Gray 2002, 8).

What Mendieta embraces is the sense of internal conflict that is part of becoming and being a self-aware environmental subject, the sense of cognitive dissonance experienced at a daily level when we cannot reconcile our ideals with our actions. A commonplace example would be the way people are told that using an airplane requires enormous amounts of fossil fuels, producing large amounts of carbon dioxide, which in turn accelerates global warming, and yet millions of people still go on holiday to beautiful and desirable natural places in the world. Whilst lying on a beach, or even admiring a rainforest's ecological diversity, high resource-consuming individuals know that their presence in a place (and their general lifestyle) is a cause of the likely destruction of that environment through climate change, pollution and so on.

Writing on environmental politics, philosopher Slajov Žižek notes that this type of cognitive dissonance is underpinned by a psychological fantasy, that of the "impossible gaze",[2] whereby there remains a strong, yet fantastical, cultural archetype of an idealised natural world uncorrupted by mankind as part of environmental culture and politics. This pristine wilderness relies on the absence of people who are therefore incorporeal "spectral entities observing the 'world without us'" (Žižek 2011, 82). For Žižek the impossible gaze manifests at a point where the subject attempts to empathise with the object of desire, the *other*—in this case nature. However, he notes that by totally identifying oneself with the other and looking out from its perspective, the other in fact disappears from view to be replaced by a view of the original subject. This is the utopic fantasy of what it would mean to lose oneself in the object of desire, nature, only to find it will have disappeared from sight and has become a cultural artefact. However, given the urgency of environmental imperatives it is equally problematic that this process of empathic identification with nature should not be attempted, as wanting to be absent from nature is to abdicate responsibility for it and the environmental challenges it faces from humanity. This situation describes the double bind of the environmental subject (that Mendieta indicates) where the individual desires both presence and absence, creating a contingent identity at a point of balance between life and death.

Another artist whose work illustrates the functioning of impossible gaze at a larger scale is photographer Spencer Tunick. Tunick is well known for his photographs of nude people en masse. Many images show people standing or in action, but a significant proportion show the subjects lying with eyes closed as if dead. This is further implied where they are set against the backdrop of a sublime nature (glaciers, the sea, forests) or lying down in an empty street. In his work *Dead Sea* (2011) the inference of death is both stronger, given the name of the work, and ambiguous at the same time, as a large group of naked people float in an in-between state on the surface of the water of the Dead Sea in Israel (the sea is famous for its high salinity, which gives an extra buoyancy to the human body). In *Dead Sea* Tunick links his work strongly to an environmental cause, stating the project was a protest against the drop in levels of the sea due to the diversion of the River Jordan which feeds it for human use. In doing so he linked the project to the competition, the "New 7 Wonders of Nature", an online global conservationist campaign, thereby locating the Dead Sea as a competitor in the "finals" alongside twenty-seven other threatened natural places around the world. In general terms, Tunick suggests that his photography:

> Stages scenes in which the battle of nature against culture is played out against various backdrops, from civic center to desert sandstorm, man and woman are returned to a preindustrial, pre-everything state of existence. (Tunick 2013)

Dead Sea and other works by Tunick therefore paradoxically create (and commercialise) a spectacularisation of nature in the global media and at the same time argue for its preservation in some original natural state for the benefit of humankind. This is therefore another manifestation of the impossible gaze which, like the people floating in the Dead Sea, leaves us in a form of environmental limbo.

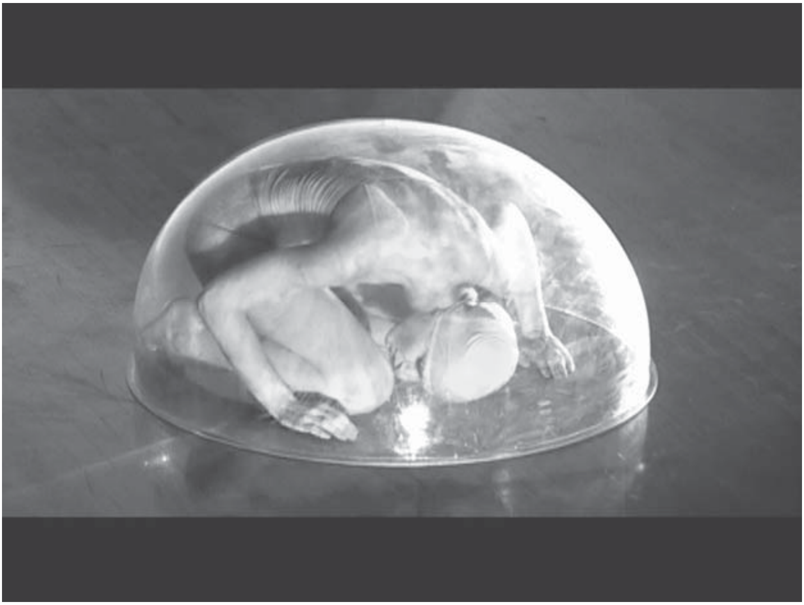

Fig. 17-1 Sarah Jane Pell, *Undercurrent*, 2007

Some artists have gone further than Mendieta's and Tunick's metaphorical gestures in their discourse on environmental politics by placing the body at a site of actual terminal risk in their work. In her performance, *Undercurrent* (2007) (Fig. 17-1), Sarah Jane Pell makes oxygen visible and corporeal as an invisible human asset in common.

> The body is suction-sealed inside a 45cm transparent dome containing 16minutes of air…The performance concludes when either a) the air depletes, b) poisoning occurs, c) 25 minutes passes. Emergency oxygen and a first aid attendant should be present. Post-dive recuperation and body monitoring is employed. (Pell 2007)

Pell conceives of the perspex dome as a prototype individual "biosphere", to protect against an external degradation of the environment. Inversely, the risk element in this claustrophobic performance encapsulates a real sense of individual contingency in the face of universal threats to human existence such as declining air quality, a factor beyond the control of one person and a matter of action at a global level.

Similarly reacting to another global threat, the artist James L. Acord responded to the destructive potential of nuclear energy by getting closer to it, becoming the first private individual in the US to obtain a licence to handle nuclear materials. Proud of his achievement, Acord had his licence number tattooed on the back of his neck (almost inevitably recalling the tattooing of numbers on Auschwitz inmates before their mass execution). Acord's motivations were mixed: he saw nuclear energy as positive but was cynical about both the technocracy that controlled it and the realities of radioactive waste which would remain dangerous for thousands of years. He wanted to build:

> A monument that would entrap radioactivity from waste dumped at the Hanford nuclear site in Washington state. He imagined uranium rods encased in carved granite rising out of a sunken sculpture, which contained the leaking material. Acord hoped it would warn future generations of the hazardous matter lurking beneath. He intended the monument to be the first of many that dealt with nuclear waste while also acknowledging its dangerousness and longevity. It was never made. (Austen 2011)

Acord got as far as making a sculptural element for this unfinished monument entitled *Monstrance for a Grey Horse*, which has two holes in the base for the radioactive material but never got as far as combining it with live nuclear elements. In 2011, Acord committed suicide after a period of ill health. According to a friend, Acord was an artist who "had been flirting with death in one way or another for as long as I knew him" (Michaud 2011).

There seems to be plenty of evidence that these types of threats to life, such as the disposal of nuclear waste created by the energy industry and the compromising of air quality, create feelings of powerlessness for many, not only in terms of their immediate threat and the physical scale of remediation needed but also by their overwhelming temporal scale, as they threaten humanity well into the future. Ulrich Beck describes this upscaling of both the perception and fact of risk which has taken place since the globalisation of society and builds on the knowledge of dangers to the individual by bringing transnational risks to the forefront of public concern:

> By their nature they endanger all forms of life on this planet. The normative bases of their calculation—the concept of accident and insurance, medical precautions, and so on—do not fit the basic dimensions of these modern threats. Atomic plants, for example, are not privately insured or insurable. Atomic accidents are accidents no more (in the limited sense of the word "accident"). They outlast generations. The affected even include those not yet alive at the time or in the place where the accident occurred but born years later and long distances away. (Beck 1992, 22)

Conceptualising these generational timescales is difficult. However, one attempt to frame individual human life set against the extended time span of ecological risk is part of a project currently being developed by Ruralrecreation,[3] a loose affiliation of artists including myself. *Lyme Light* (2011-) is a project in development for Lyme Regis in the UK which aims to temporally reconfigure this matrix of environmental subject, population, energy, life and death. The proposal is for a computer-controlled LED streetlight on the seafront in Lyme Regis to be connected to information from the local registry office so that it changes to a particular colour on the anniversary of births and marriages in the parish, and extinguishes itself on the anniversary of a death (Fig. 17-2). The project can be described as an attempt to integrate individual death and life back into the infrastructure of public space as recurring phenomena where the everyday death of ordinary people is minumentalised (in opposition to the familiar monumental epitaphs of public death which monumentalise the life and death of official VIPs). Temporally, the context of the project contrasts timescales of individual human life with the extended geological timeframes and mass extinctions which are recorded by the Jurassic fossils in the cliffs above, which make the town world famous.

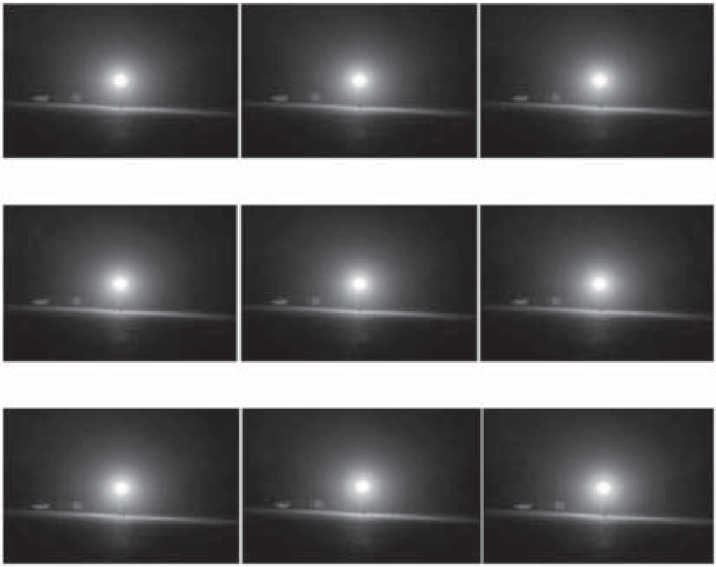

Fig. 17-2 Ruralrecreation, *Lyme Light*, 2011-

The Ruralrecreation residency in Lyme also generated a temporary project *Lines of Flight* (2012) which was another iteration of the core theme of ecological time. In this case a sequence of hollowed-out mirror balls are bolted to a lamppost in a spiralling sequence reminiscent of models of DNA (di-nucleic acids—constituents of genetic material) (Fig. 17-3).

This symbolically connects the work to the demonstrable effects of genetic evolution over geological time contained in the fossil record nearby. Functionally the mirror balls serve two purposes, at night the mirrored surfaces reflect light from the lamp above to provide a decorative lighting effect that represents zero net expenditure of energy from municipal energy provision. At the same time, the hollowed-out interiors are also able to accommodate nesting birds, allowing the infrastructure to mitigate in an ecological sense against the environmental depletion of habitat caused by consumption of natural resources for energy by the human species.

Fig. 17-3 Ruralrecreation, *Lines of Flight*, 2012

Both projects aim to reconnect with the commonness of life and death and reinvest these aspects back into the common public realm. In doing so these works address the fears of the individual—the sense of contingency that he/she has in the face of the overwhelming presence of the other (measured in billions across the globe) and prompts the question, “What can I as one person do that will make a difference?”. An answer indicated here is the recognition that, in order for the individual to feel capable of addressing threats in common to populations, that individual must firstly be able to address that population on the basis of possessing an equal stake and voice in common space (and that these rights should be extended to the other species that cohabit the planet with us).

Without a sense of social justice at the core of environmental and ecological politics then, to return to Gray, the only alternative seems to be to think of humankind as a pathogen needing a cure at the level of populations. This though seems like a dangerous extension of biopolitical logic. Direct control of population growth by human agency in the past has often directly been associated with totalitarian projects, the fascist eugenics of the Nazi regime or the One Child Policy of communist China. Even today there is the forced sterilisation of women in Uzbekistan not only as a means of population control but as a bizarre effort to reduce maternal and infant mortality rates (Antelava 2012). In contrast, reproductive rights are asserted in most democratic neo-liberal countries: “The basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children” (United Nations 1994). The only other environmentally friendly alternative to overpopulation then is negation of individual reproductive rights, another form of self-destruction although at the level of the gene, and an act which rejects the neo-Darwinian thinking of scientists such as biologist Richard Dawkins who give primacy to the perpetuation of genetic material within populations as the ultimate function of life and procreation.

Control of life at a genetic level and the modification of human, animal and plant populations has become a major environmental concern, as witnessed by ongoing protests against genetically modified food crops developed in the name of food security by multinational biotechnical companies. Equally, the promise of customisable humanity has framed serious ethical and political questions around the boundaries of human identity and the commercialisation of shared genetic heritage which should be held in common. Shiho Fukuhara and Georg Tremmel play with these themes in a transgenic art project called *Biopresence* (2004) which “creates Human DNA trees by transcoding the essence of a human being within the DNA of a tree in order to create ‘Living Memorials’ or ‘Transgenic Tombstones’” (Fukuhara and Tremmel 2013). In this project there is a literal symbiosis which manages to evoke both the terrifying horror of uncontrolled mutation and subsumed identity, and a form of ecological transcendence as it follows the logic of complete, holistic integration of humanity into the environment—a symbiosis that takes place even after death.

In these artistic projects then it is possible to travel through Gray’s pathogenic model, from our current experience of a chronic infection that needs to be dealt with before the host is destroyed, to the utopics of a homeostatic symbiosis, to visions of self-destruction and mass mortality and an imagined final and absolute symbiosis with nature in death. All of these visions though must overcome somehow the fantasy of the impossible gaze, of death without dying, of both presence within a natural world and absence for the environment’s sake. Environmental art can thus be compared to Persephone, the goddess from Greek myth associated with the harvest, who spends six months of the year on the Earth and six months of the year in Hades, the underworld, endlessly moving between life and death. As such, Persephone describes the oscillating state of the environmental subject, of society, and of art itself which places us between what Lacan would describe as the real of our own fictions and the unobtainable Real of nature, our state before language and art begins.

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Notes

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[1] Mendieta’s emotionally charged art prefigured her own death which was equally shocking, as she fell from her New York apartment window after a fight with her boyfriend, artist Carl André. Possibly suicide or an accident, André was acquitted of her murder (O’Hagan 2013).

[2] Žižek here is referring to Jaques Lacan’s discussion of the subject’s fantasy of presence at its own birth as part of the construction of individual identity in relation to society—seeing oneself as a subject (Lacan 1977).

[3] www.ruralrecreation.org.uk

CHAPTER EIGHTEEN

THE LAST PHOTOGRAPH: A MICROSCOPIC VIEW OF TRANSIENCE, MOURNING AND LOSS

LUCY WILLOW

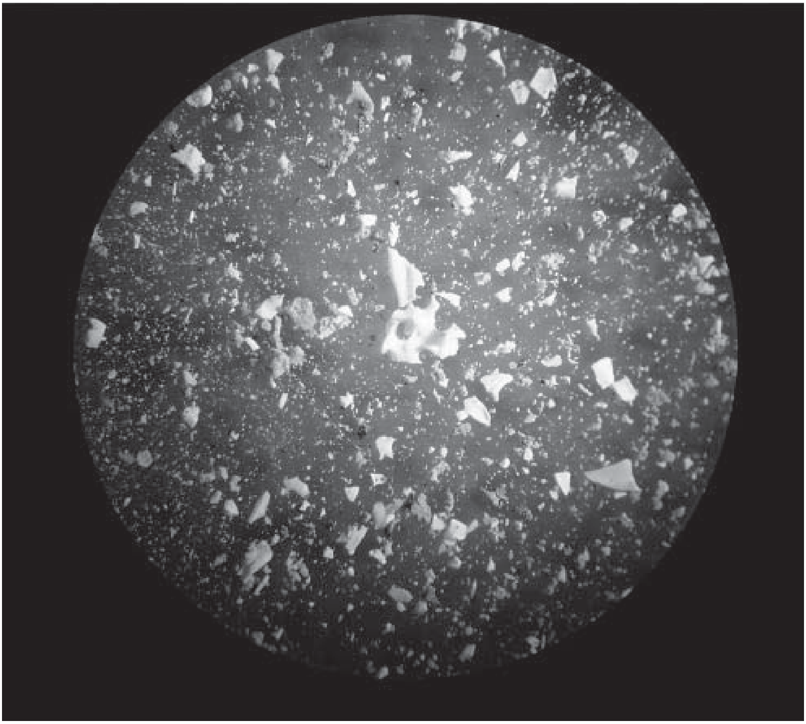

Fig. 18-1 Willow, Lucy, *The Last Photograph*, 2006

> "All photographs are *memento mori*. To take a photograph is to participate in another person's (or thing's) mortality, vulnerability, and mutability. Precisely by slicing out this moment and freezing it, all photographs testify to time's relentless melt." (Sontag 1979, 15)

I am brought back into life through studying death, transported into the present moment, into the now. As an artist I have always been interested in dark transgressive imagery, inner melancholic landscapes, death and the awakened states of feeling that can accompany it. The lens of the camera has allowed me to examine the bloody carcasses of road kill and rotting birds brought in on the tide. The experience is one of great intensity, nothing existing beyond the direct relationship between the animal and myself. Recently these discovered deaths have been translated into drawn environments and animations, transcribing the imagined marks of mortality into a series of artworks. Through animation, I was able to breathe a soul back into a dead goldfinch that had flown into a window; to make it temporarily come to life; to watch its breath in silence. I was waiting, sensing; being present, reflecting on its passing and mine. Exploring loss, and the profound beauty that can be found in a transient moment such as death, brings with it an appreciation of life and all that passes through it.

The imagination can, at times, be catastrophic. It throws us into the realm of nightmares, the place of *what ifs*: the most monstrous of all these dark fantasies being death. As a mother, the imagined death of a child becomes the most catastrophic, deplorable and unspeakable reality, conjured up in the darkest depths of our imaginings. We are unable to comprehend the continuing of life, should such an event occur. Yet we know that these events do occur. The loss of children and young people occurs on a daily basis through accident, war, starvation, illness, murder and abuse. It appears to be something remarkably strange in the Western human psyche that each individual feels immune to tragedy until it happens. And, when it does, we are generally ill-equipped to deal with the aftermath.

95.1 percent of the total content of the universe is labelled "dark matter", astronomy's greatest mystery, unknown and unseen. Its shadowy uncertainty neither emits nor absorbs light, nor any other form of electromagnetic energy. It is simply felt. Its dark gravitational pull affects the things that we can see; affects what we know. Grief is like that: the dark matter of bereavement. Like most, I was unprepared when my son died in the summer of 2006, leaving behind a perfectly sized and proportioned hole in my universe. On 7 September 2006, his ashes were returned, hand delivered in a mauve plastic jar with a screw-topped lid. The label read: *Penmount Crematorium, crem. no. 106298, 1st September, Jack Justin Perry*.

Silence fell and settled on me with an immeasurable lethargy and weight. I stopped. People were moving around me, going about their day-to-day lives, while I remained motionless. I was balancing on a tightrope between breaths, where nothing made any sense. There was no right order, no fairness, no logic, no more day-to-day problems and no petty arguments. Emptiness replaced the life that was there before. In those early days of grief, there was no past, no future, no feeling. I was in a waking coma, a dream that had no correspondent reality.

I felt close to the Victorians and their intimate relationship with death. At the point of departure, I would have drawn the curtains, stopped the clocks, and turned the mirrors so that I could watch over his body night-and-day until his funeral, if I hadn't been so numb with shock. The veil between life and death felt very thin, the slightest gust of wind able to blow it aside. In the years following Jack's sudden death, the cult of mourning became a way of life. My house was filled with fetishist mementos from cultures that had a more direct relationship to death. Mexican "Day of the Dead" brightly painted edible skull sweets and skeletons, formed shrines around the house. Through my art practice, I invented elaborate rituals, which enabled me to come to terms with loss.

For a number of years death has been present in my life and art practice. I have a freezer full of dead animals, mostly birds that have been given as gifts. Whilst out walking, I take a bag to collect dead animals, picking up whatever I find. I am used to the smell of dead seabirds, a pungent aroma mixed with the salty, fishy air. I am particularly fond of dead birds and the relationship human beings have to them through mythology. Birds feature strongly in superstition, bringing us luck or sorrow, depending on the species. In folklore they represent spirits or angels, supernatural aids, states of higher being. The human soul in mythology is often seen as a caged bird. In fairy tales, birds talk. Birds are universally recognised as intelligent collaborators with us in myth and folktales. Birds are seen as messengers, able to fly between worlds. Finding them dead or taxidermied, I can examine the narratives up close, subverting the mythologies and placing my own symbolic language over the top. Particular species: magpie, canary, crow, goldfinch, black swan, robin and the sparrow, are all used metaphorically to communicate a particular narrative within my artwork.

For a while, following his death, Jack took on the form of a canary: delicate and precious, with a hypersensitive heart, accompanying miners deep into the earth. As an early warning system for danger, the delicate bird would react to toxic gas, such as carbon monoxide, methane or carbon dioxide, and die before it affected the miners. The canary spoke to me of the tragedy, sadness and fragility present in the midst of life. Finding ways to live through bereavement, I took photographs of the death that was around me, submerging myself into a deep reflection on sorrow.

In 2009, I began a photographic series of work titled *Memento Mori* ("remember that you are mortal and will die") based on the melancholic symbolism of seventeenth-century Dutch Vanitas paintings. Appropriating the symbolic language found in these paintings, I was looking to draw attention to the parallel beauty found in both life and death. The images contained rotting fruit, decaying animals, bubbles, extinguished candles and jewellery to serve as a reminder of the transience of everything in life. The paintings held, within them, an understanding of a narrative from seventeenth-century culture, which warns against the vanities and temptations in life, such as wealth, knowledge, lust and earthly pleasure. The narrative emphasises how we ought not to be distracted by these, but remain focused on the spiritual, the afterlife. I borrowed the symbolism in order to examine mortality.

In the reflection of a sad and moth-eaten taxidermied magpie I saw my own grief, resting between its tatty feathers as I photographed its stuffed corpse. I bought a lamb's heart and placed it in the centre of a still life, to signify young loss, vulnerability and sadness. I hid any outward signs of mourning amongst a symbolic visual language that found its expression in the photograph. What else could I do? Working into the surface of the photograph with water, I was able to bleed and merge the colours, giving the surface a visceral, opulent quality that made the image feel as though it was disappearing and rotting in the presence of the viewer. The colour was an externalisation of what was happening, on the inside of me: the feeling of dissolving. I was looking to understand death through the arrangements of objects I assembled and photographed. An event, once photographed, becomes more real. I photographed death looking to insulate myself against its devastating impact, feeling its omnipresence intimately in the midst of life. A photograph confirms reality. The scythe of death cuts through all the unnecessary in life, bringing us to stillness at the core of our being, where nothing else exists but a silent longing for the peace it brings.

Death, like birth, is an experience that cannot belong to us; we cannot be consciously present at either. We cannot hold our own death; we can only witness death in the "other". The other is the one that can die. I was observing the otherness of death held in Jack's ashes that day. If a tree falls in the forest, it makes no sound unless we are there to witness it. The sudden death of someone you love is as unbelievable as a tree falling and making no sound.

In hindsight, I wish I had felt able to photograph Jack at the time of his accident and in the days that followed. I wonder whether the act of photography enables you to stay witnessing an experience, to be present, to digest, to give shape to something that is too terrifying to bear with the naked eye? Perhaps it gives you agency in the face of such powerlessness and devastating loss. As an artist and a mother, my deepest instinct was to photograph Jack. I wanted to bear witness from behind the lens of the camera. I could observe, in silent communion, the bruises on his body. I could hold his wounded broken corpse in a photograph; heal the internal wounds opening up inside; touch the untouchable. Death however has become alien and frightening. The lens protects. It creates a screen, through which to observe the contours of the body from a distance, but the post-mortem photograph has become a taboo, considered morbid and macabre. It felt wrong and secretive, as though I would be betraying the trust of my family and friends. They were used to my art practice, but not in this context. I behaved according to what I felt was socially, psychologically and emotionally acceptable. Death is no longer permitted to share a space with the living.

In the days following the arrival of Jack's ashes I made an arrangement to visit my father's marine biological lab in Bath, to observe his remains. I wanted to take one last photograph.

> *A team of young marine biologists greet me; my father leads the way to a free microscope with a digital SLR camera attached. He introduces me to his team as "my artist daughter" therefore giving me the right to do as I wish with Jack's ashes, unhindered, unquestioned. I enter the lab. I take a little of his ash out of a purple silk bag, mindful not to lose a spec of the precious material, scraping any residue from under my fingernails. On September 26th 2006, Jack was looking back at me from under a laboratory microscope. I look to see if his ashes contain any information regarding his mysterious whereabouts. I have become a forensic scientist, looking for clues. Evidence has to be gathered. I make notes, take photographs; I am searching for answers to unbearable questions.*

Mourning, as described by Freud, involves a process of shuffling and rearranging; examining and re-examining; taking each memory and looking at it from as many different perspectives, from as many different angles, as it takes for the process to exhaust itself. We meet each memory, each hope, and face it without that person present. Our internal world is in the process of rewriting itself. Remembering prolongs the existence of the one lost.

Ash is not as I would have imagined it; it is dense and coarse, not at all like dust. I am familiar with dust. I have collections of it: Hoover bag dust collected and dated from 2001-2007; marble dust; coal dust. Like stardust they have fallen containing the invisible histories of all that has moved through my life. Dust, I feel its silent presence in the air; the smell coating the inside of my nostrils; like a phantom gathering on my skin. It lines the sink and bath; a thin blanket of shattered moments; the debris of a discarded life. A visitor passing through, escaping through cracks in the wall, leaving behind a trace that gathers softly. A fine stratum of time, layered over books and shelves, keeping its ethereal mystery. The emptiness of life is embodied in dust.

Making drawings of dust, I hoped to glimpse at its secrets. With no endings and no beginnings, it offers up a liminal space, possibilities beyond boundaries. It escapes. I recognise all that I do not know, losing myself in its presence. It moves around the house on the lightness of air, like a daydream passing through and then forgotten; spiralling on shards of light, and then gone. The sadness comes with the voices it echoes, the voices of the abandoned. It whispers without sound, haunting the spaces it occupies. The daydream urges me into an unknown internal landscape of endless possibilities, where death does not exist, where the beauty and grandeur of dust settles on my inner thoughts like snow. A subterranean world of wounded joy; where sadness and loss occupy the same space as bliss. Working with dust urges me towards the irrational, a formless, fleeting state that is indefinable. It is the evidence of loss and impermanence present in life, untamed and lawless, existing in neither one state nor another. Exuded by death into the world of the living; awaiting us at the end.

Whilst travelling in Northern India in 2000, I saw a Tibetan sand mandala, beautiful and intricate. When presented to the Dalai Lama, he made a mark across the surface with his finger and then discarded it, scattering it ritualistically. It fell as a blessing on all it touched, a profound reminder of the impermanence of everything in life. I use collections of dust in a similar way, to make ornate and patterned carpets (2003-2007). Responding to a particular site or context (an empty house, a church, an abattoir or gallery space) I lay it directly onto the floor and etch intricate drawings with a fine paintbrush into the surface. *Marble Dust Rug* (2005) sat between four steel columns in Smithfield abattoir, appropriating imagery from Hieronymus Bosch's *The Garden of Earthly Delights* (1490-1510). Everything was falling, the marble structures returning to dust.

Freud believed that the more transient an experience, the more pleasure we derive from it. The fleeting observation of a dragonfly, appearing for a while with its translucent, iridescent colour, or a flock of starlings returning to roost, delight us with their momentary appearance. The carpets of dust exist for a short period of time before being swept away at the end of the exhibition period. Drawn to questions that confront society's attitudes towards death, the dust carpets seek to expose what lies hidden beneath the surface, the attitudes and emotions we wish to sweep under the carpet. Working with the poetry of transient materials reflects the belief that there is nothing lasting, immortal or permanent, within life or within us. Can the beauty and joy of life perhaps only be known subsequently to witnessing death and the transient nature of everything?

The lens of a microscope acted like that of a camera. I was able to confront the uncomfortable, to bear witness from a distance. I wanted to see into and beyond his death. I was looking to understand the "otherness" of death. Looking at death through a microscope, I examined all that now remained, my eyes moved over his rocky surface. I was looking for something more in Jack's ashes. I was not attempting to capture the transient moments in life or to capture what was disappearing. I was searching for answers, like a Victorian spiritualist, hoping for some kind of visual resurrection through the image. Perhaps a ghostly form would make itself known to me. Through the microscope, I was examining death to see if I could make any sense out of such profound loss. In the photograph, we are presented with an opportunity: to explore the power of the image to re-examine the past.

It is hard to give up the physical body. Precious and beautiful, I would have liked to treat it with reverence; bathed, dressed and cared for it at home. I wanted to keep it. I had visions of running away with it on the way to the crematorium; floating with it out to sea, finding a new place to live where I would put him in a freezer and stay with his body for eternity. As a mother, it was hard to give up the body, the body that came from my body. It is hard to surrender his ashes to one spot too. It was once considered a great honour to care for the dying. With tender loving care, the deceased would be dressed and laid out by family members, peacefully, as if frozen in eternal sleep. The metaphor of sleep was comforting to those in mourning. It was less frightening than imagining the dark matter of death, the great, unknown chasm of emptiness that opens up in the space the person has left. There, in the comfort of the home, the body would wait while relatives mourned and said goodbye. Does being raised in a post-religious culture—with few rituals surrounding death, where someone is paid to provide a funeral service, with no personal handling of the body and little open discussion around dying—make it difficult to know how to approach death when it comes?

I was unaware, at the time of Jack's death, of cultural practices that embraced the desire to be remembered in death. I recall being stunned and profoundly moved to discover the Victorian cult of photographing children following death, a once widely accepted and popular practice. Children were dressed and laid out as if in a deep eternal sleep, waiting for the afterlife. They were captured in a sacred transition, at peace, as angels. Death in the Victorian era was not a taboo; it was photographed, discussed and talked about. Capturing a person's soul and keeping it alive, forever in the hands of whoever held the image, enabled the bereaved to hold onto the young life that had been lost. With death follows the thought, "if only I could have one last conversation, one last photograph, one last time." It is easy to imagine how convincing the spirit photographs would have been amongst those who wanted to believe. The ghostly presence of a lost relative could be seen in countless images: scenes of suspended animation, floating, hovering and visibly present.

As an artist, and through my personal experience, I seek to address the distance and alienation we have to the body after death. Following the mass deaths and uncountable numbers of bodies seen after WWI, profound changes were seen in the way communities mourned. Mourning began to be internalized; it saw the beginning of wearing grief on the inside. How do we collectively share grief, having lost the symbolic mourning codes and ritualistic practices that once allowed us to read the emotional lives of others? Shared grief is important. We pass each other, unaware of the internal grief and suffering we share. All human society needs mourning rituals involving a public display and recognition, a witnessing and validation of loss. Without mourning rites, death becomes meaningless. I found no spoken words adequate to communicate what was going on internally. The only way I knew how to address how I was feeling was through the process of making and opening up a wider debate relating to mourning and bereavement. Do the arts allow us access to grief and the possibility of tapping into our own private losses? Can they publicly demonstrate how creativity can emerge from turbulent, destructive, sorrowful and bereaved states?

I look at how artists photograph death, seeking permission to find a voice for what I am unable to say with words. My visual practice penetrates the tangled emotions felt when talking to others, removes the consideration I have for their sensibilities. It is hard to speak about what you have witnessed; the image has the power to give voice to what is unspeakable. We are used to images of bodies. Photographers, such as

Don McCullin, have focused on dead bodies as a result of war, genocide, ethnic cleansing and violence. He is able to capture the immeasurable suffering of those starving or close to death.

As an artist and a mother, the most natural instinct I had was to turn the camera upon Jack. The camera, it seems, is a way to record the final moments with someone, a lingering goodbye. With a camera, I could have caressed each part of his body with great love and sensitivity, moving it gently over his feet, his hands, his face; remembering and communicating all that I felt unable to say in words. To give voice to a silent experience, one that is hard to discuss openly and freely, is perhaps a way to ward off depression and the haunting loneliness that illness and death can bring. As a way to share a universal experience not easily expressed in words, the image can pierce the wall of silence, opening up the possibility of connection to others. I want death, as it did in the Victorian era, to share a place with weddings, events, births and the everyday. Nan Goldin believes that you couldn't lose anybody if you photographed them enough. The photograph is a way to integrate the memory of the dead into the present, into on-going living, into the future.

I saw a future through the microscope that day. Following death, certain aspects of the other person's life come sharply into focus. I wanted to know all the facts, examine them, and draw them up into my consciousness. All the last details, the last food that was eaten, the last conversation, the last clothes worn, the last objects touched, the last people seen, the last journey made, the last breaths taken. In the early days of grief, the details of the other's life is scrutinised, drawn into microscopic focus, imagined and re-imagined. With microscopic vision, nothing else is allowed in. Alone with the microscope, all else can be shut out, avoided, in a private world where I could silently be present with all that remained. Words are not enough to communicate what is felt following death. A photograph can be passed on and witnessed by another, in silence. Empathy and shared experience pass between each other without words. The image speaks without words in a profound and intimate way, revealing what we sometimes close our eyes to.

I treated Jack's ashes as the Victorians treated the body after death: adorned, worshipped, sacred and precious, all 8lbs of them. They have the texture of soft grey sand with shards of white within. You can see fragments of bone with the naked eye. Ash is surprisingly comforting. The scattering of ashes is not so much about letting go but an unspoken promise to keep the future, between us, alive. They can be scattered, a teaspoon at a time, to all corners of the earth, the wind carrying it continually on to new places. They are light and freeing. The inheritance of Jack's life and memory is contained within his ashes. He has fallen from the leaning tower of Pisa, been scattered from a cruise liner off the shores of Iceland in the midnight sun, sat on the main stage at Glastonbury, floated in the canals of Venice and been carried on the wind at the top of Mont Blanc. He has been to New York, ridden in the back of a limo and been placed lovingly under the boardwalk at Coney Island. He has been in every ocean. He has seen twenty-one locations simultaneously on his twenty-first birthday, from Australia to Edinburgh. He has been bottled and set downstream in rivers. He has been carried in jewellery, placed in temples and left in cathedrals in Spain, Italy and Quebec. He has ridden on roller coasters; he has been tossed from Brighton Pier and Beachy Head. He has been held by children, friends, family and strangers. He has even been thrown on stage and caught by Nick Cave during a concert in Brighton in 2008. In death, he is everywhere.

The microscopic detail revealed within it something universal and unchanging, transformative and freeing. Suddenly I was not looking through the lens of a microscope but instead the lens of a telescope. The space between his bone galaxies was inflating and he was moving with it. I was looking up at the stars. Through the backlit Petri dish, I saw the individual particles opening out and moving away from one another. In death, he was expanding. He was getting bigger, everywhere, not confined to a body in time. I saw the unravelling of the universe. The series of microscopic post-mortem photographs taken that day have allowed me to live through his untimely death.

The photograph goes hand-in-hand with family life, constructing a narrative through the family album. We record all the significant events and achievements of our children's lives, except death. Part of my album was missing. The image has the power to separate something important, from everything else. It allowed me to frame death differently. The last photograph has become a mediation that is confirmatory and life affirming. When I look at it, I am looking up at the stars; I am looking at the past, at Jack, at death, at all I do not know, in wonder.

> When he shall die, take him and cut him out in little stars, and he will make the face of heaven so fine that all the world will be in love with night and pay no attention to the garish sun. (Shakespeare 1992, 82)

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