Malady and Mortality

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Illness, Disease and Death in Literary and Visual Culture

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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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ILLUSTRATIONS

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Michele Aaron's chapter is a revised and shorter version of Chapter 6 of her book, *Death and the Moving Image* (Edinburgh University Press, 2014).

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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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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-