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### A literary perspective

#### Overview

Anne Whitehead

Rita Charon, Professor of Clinical Medicine at Columbia University, has notably observed that it is neither possible nor desirable to define the relation between literature and medicine solely in relation to the emergence of the medical humanities as a recognizable field or discipline; rather, she argues, their connection 'is enduring because it is inherent' (Charon 2000: 24). Charon has played a leading role in creating the movement of narrative medicine, which is centrally concerned with opening up new approaches in medical education, and its core principles are encapsulated in her monograph *Narrative Medicine* (2006).<sup>1</sup> For her, the clinician's task is essentially one of narrative interpretation: the doctor is required to listen attentively to a complex and multi-faceted narrative, told in the patient case history, in the symptoms of the body, and in medical images and laboratory test results, all of which need to cohere into the formulation of a diagnosis and treatment plan.

Medical education should therefore aid the development of key narrative capabilities, defined by Charon as 'recognizing, absorbing, interpreting, and being moved by the stories of illness' (Charon 2006: 4; my emphasis). Moreover, for Charon, narrative should not only be read by the trainee practitioner but also written by her, in the form of a Parallel Chart that records what her patient endures. This, Charon explains, allows the medical student to 'enter the worlds of [her] patients, if only imaginatively, and to see and interpret these worlds from the patients' point of view' (Charon 2006: 9; original emphasis). For Charon, then, narrative – whether read or written – is valued because it is productive of empathetic engagement with the patient.

Charon's work, which has proved highly influential in the rapidly burgeoning field of the medical humanities, comprises a compelling story about the literary, which is seen as an inherently narrative medium. It also shows the literary medium to be essentially humanizing, equipping students with 'compassion' (Charon 2006: 8), although Therese Jones rightly encourages caution about such assumptions in her introductory chapter within this volume. Charon's story, however, does not take into account historical and theoretical shifts in how literary narrative has been

conceived. It also produces an account of the literary as enhancing what the medical practitioner already does. In the words of Martyn Evans and David Greaves, narrative is privileged because it can 'foste[r] clinicians' abilities to communicate with patients' (Evans and Greaves 1999: 1216). In what follows, it is my aim to reorient these two assumptions, which are embedded not only into Charon's work but also into a central strand of the field in the United States (US) and the United Kingdom (UK).

My argument will trace a brief history of how changing perceptions of narrative have shifted the relation between literature and medicine in the period since 1945, even as related changes in medicine have also inflected how the two terms intersect. While I do not seek to deny that there is an 'enduring' relation between literature and medicine, I contend that it is nevertheless important to historicize that relation. Within the scope of this chapter, this involves recognizing that the medical humanities coalesced as an identifiable field at a certain historical moment: in the 1970s in the US and, in a delayed response, in the 1990s in the UK. I argue in turn that we can productively distinguish the characteristic approach to literature that defines the medical humanities apart from earlier developments, which we can see as signs of what was to come, but that we should not retrospectively retrofit in relation to the contemporary moment. I also respond to the medical humanities from a specifically literary perspective, indicating aspects of literature that might enable the field to shift from what Evans and Greaves have termed 'an "additive" view, whereby an essentially unchanged biomedicine is softened in practice by the sensitised practitioner' towards 'an "integrated" view whereby the nature, goals, and knowledge base of clinical medicine itself might be challenged and reshaped by its encounter with the humanities (Evans and Greaves 1999: 1216).

The first half of my chapter draws on Lars-Christer Hydén's work on illness and narrative to trace a postwar history of changing approaches to narrative, and their influence on how the relation between literature and medicine is conceived. Following Hydén, I distinguish between an early attention to the study of narrative 'in clinical practice' and in relation to the 'doctor's experience', and a subsequent shift to interest in 'patients' experience of suffering' (Hydén 1997: 51; my emphasis). I exemplify these trends through the studies of Michael Balint and John Berger in the 1950s and 1960s on the role of the general practitioner, and through the rise of the literary genre of pathography in the late 1980s and 1990s. In the second half of my chapter, I turn to the present to assess the main challenges and areas of potential within literature for the medical humanities. I examine first the arts in healthcare movement in relation to literature, particularly creative writing, and analyze the question of evidence as a central methodological concern within the field. I close by examining the current shift in the field towards the 'critical medical humanities', as discussed in Alan Bleakley's introductory chapter within this volume, asking what this might indicate in turn for its future direction and potential.

### Postwar beginnings

In tracing the emergence of the medical humanities, Ronald A. Carson has argued that they are 'a product of the turbulent '60s, when authority and expertise were being questioned and traditional ways of doing things were being challenged' (Carson 2007: 322). Clinicians were particularly concerned about the increasing 'technologisation' of medicine and intensifying 'bureaucratic and market pressures' on clinical care, and they turned in response to the humanities as a source of reconnection (Carson 2007: 329). In what Hydén and Elliot G. Mishler have identified as a linguistic turn, attention was directed to 'the forms and functions of language in medical practice and training', and early research in this field, dating to the mid-1960s, focused in particular on the ways in which 'physicians may improve their communication skills so as to more effectively perform their clinical tasks: history taking, diagnosis, and treatment' (Hydén and Mishler 1999: 174). As Hydén further elaborates, in these early studies 'the illness narrative itself was a secondary concern'; of primary importance was whether doctors could, through illness narratives, 'become better able to attend to what their patients say' (Hydén 1997: 51–2).

In the British context, the pioneering work of Michael Balint at the Tavistock Clinic in London represents a significant early reorientation of the medical towards narrative. Balint trained as a psychoanalyst in his native Hungary, and developed there a belief that the psychoanalytic method could be utilized across a range of medical treatment settings. In London, Balint set up discussion groups in the early 1950s for doctors interested in importing a modified version of the 'talking cure' into general practice. In 1957, Balint published *The Doctor, His Patient and the Illness*, in which he introduced his novel ideas for the doctor's relationship with the patient. Analyzing the impulse towards diagnosis as often premature and as acting for the doctor's benefit, relieving him of 'the burden of either not knowing enough or of being unable to help' (Balint 1964 [1957]: 231), Balint advocates instead what he terms 'the long interview', in which the taking of a medical case history would be replaced by a more extended process of listening to the patient: 'if you ask questions you get answers – and hardly anything else. What we try to foster is the growth in doctors of an ability to listen to the events as they develop in the doctor-patient relationship during the interview' (Balint 1964 [1957]: 288, 133; original emphasis). Balint's work, undertaken in the context of the nascent National Health Service in the UK, can be seen from the contemporary perspective to have provided an influential model of the 'good doctor' as an empathetic listener to the patient's narrative, and as a professional witness to the latter's suffering.

The publication in 1967 of John Berger's *A Fortunate Man*, itself deeply indebted to Balint's study, provides a powerful portrait of the role doctors

play in their communities and of the doctor as compassionate witness.<sup>2</sup> Following John Sassall in the impoverished rural community of the Forest of Dean, we see him directly applying Balint's principles in his medical practice: 'In the evenings after supper he has long appointments lasting an hour with patients whom he believes he can help with psychotherapy. They suffer their crises with him' (Berger and Mohr 1997 [1967]: 124). Berger's analysis further reinforces Balint's model of medical practice. The process of diagnosis is one that 'includes doctor and patient', and that 'first recognize[s] the patient as a person' (Berger and Mohr 1997 [1967]: 74). Indeed, Sassall is positioned as a model of what we would now define as patient-centred care:

He never separates an illness from the total personality of the patient – in this sense, he is the opposite of a specialist. He does not believe in maintaining his imaginative distance: he must come close enough to recognize the patient fully. (Berger and Mohr 1997 [1967]: 113)

In this process of recognition, Sassall does more for his patients than treat them when they are ill; he becomes for Berger 'an objective witness of their lives' (Berger and Mohr 1997 [1967]: 109). Entrusted by the community with their most intimate, and at times most anguished, moments, he keeps the record of these experiences and so acts as a repository of memory for the community in which he works.

There is much that seems familiar to the contemporary eye in Balint and Berger, and their model for medical practice can be read as a prototype of current ideals for whole-person care and empathetic treatment. Nevertheless, we can also distinguish their work as emerging from its own particular historical moment. Both studies reflect a social context in which general practitioners can expect a long-term relationship with their patients; this underpins not only Berger's identification of the doctor as 'clerk of...records' (Berger and Mohr 1997 [1967]: 109), but also Balint's economic model of the doctor-patient relationship as a 'mutual investment company', in which 'capital assets' are built up over an extensive period of repeated consultations and treatments (Balint 1964 [1957]: 251). In this sense, Balint and Berger both capture a world that is vanishing; the stable communities that they document are already in the process of transforming into the more mobile, fractured social environments of the present. As I have also indicated, the model of narrative that is reflected in their work is similarly evocative of the specific time in which they were writing, locating its interest primarily in relation to the doctor's rather than the patient's experience.

While both Balint's and Berger's studies position the good doctor as closely attentive to patient narrative, they notably embed the process of empathetic listening within a psychoanalytic framework. The value of the

therapeutic model, however, remains a topic of debate within the current field of the medical humanities. Attention has shifted in narrative medicine from psychoanalytic to literary training over the last 50 years, with the assumption that engaging with literary texts enhances empathetic capacities and leads in turn to humane and compassionate action. In closing this section, I propose to briefly indicate some main critical responses to the literary model that Charon advances. For Geoffrey Hartman, the first doubtful proposition is that empathy can be taught as a skill, and that literature can be mobilized in this direction. Hartman accordingly questions: 'Short of pharmaceutical treatment, ... can there be empathy management, as we now have pain management? And what role could the arts play, in the light of our notorious ability to compartmentalize feelings?' (Hartman 2004: 339). Recent literary studies have also called into question whether empathy felt for literary characters translates into real-world action on behalf of others. Suzanne Keen sceptically remarks in *Empathy and the Novel*:

I ask whether the effort of imagining fictive lives ... can train a reader's sympathetic imagining of real others in her actual world, and I inquire how we might be able to tell if it happened. ... I wonder whether the expenditure of shared feeling on fictional characters might not waste what little attention we have for others on nonexistent entities, or at best reveal that addicted readers are simply endowed with empathetic dispositions. (Keen 2007: xxv)

In a similar vein, Bert Keizer questions in the medical context whether reading a novel would enhance a doctor's empathy, and what its effect on medical practice might be:

The idea that certain fictional approaches to illness would somehow improve a person's power of empathy is, I think, unfounded. ... Fiction may tell a reader what it is like to be crazy, alcoholic, depressed, constipated, paralytic, epileptic, asthmatic, sleepless, frantic, exhausted, addicted, mad, demented or scared. It is unclear to me how this telling would contain a lesson in cases when the reader is a doctor. (Keizer 2003: n.p.)

Neither critic denies that as readers we can develop an empathetic identification with fictional characters; indeed, this is often a powerful effect of the literary. Rather, the question that they raise is precisely how this response is related to broader social action, whether this comprises altruistic deeds on behalf of others or improved medical care. For my own purposes, a central problem with Charon's narrative medicine, and its harnessing of the literary to empathetic training, is that it also implies a merely additive role for

literature. It assumes, in the words of Jane Macnaughton, that literature 'helps doctors do what they are already doing in a more humane, empathic way', while leaving 'untouched' the assumptions, methodologies and practices of medicine itself (Macnaughton 2011: 928).

### The rise of pathography

I have so far argued that in British medicine, the 1950s and 1960s were characterized by a predominant interest in narrative as it connected to the doctor's role in the clinical encounter, and by a methodological turn in language and psychoanalysis. We can, however, discern a decisive shift in the conception of narrative in the 1980s and 1990s. More recent accounts of narrative focus on its function in helping us to know and understand our social world, and on its constitutive relation to identity. The publication of Arthur Kleinman's *The Illness Narratives* (1988) acted, in Hydén's view, to give this particular conception of narrative currency within the medical sphere: '[f]or Kleinman the narrative is the form in which patients shape and give voice to their suffering' (Hydén 1997: 51). If illness is a profoundly disruptive experience, narrating the story of that illness can act as a means to give it meaning, to reconstruct the patient's identity and sense of relation to the world. Moreover, Kleinman drew attention to the patient's narrative as one of *suffering*, as Hydén elaborates, narrative becomes a vehicle not only to 'articulate suffering', but also to voice the illness experience 'apart from how illnesses are conceived and represented in biomedicine' (Hydén 1997: 51). These decades also witnessed the predominance of post-modern theory within the academy, and the widespread influence of ideas such as Jean-François Lyotard's (1984) account of the collapse of grand narratives, which were seen as no longer adequate to explain our knowledge and experience. Hydén observes that this translated in the medical context into 'doubts about the possibility of biomedicine to cure ills and relieve suffering' (Hydén 1997: 49). The way was thereby paved for illness narratives to challenge the voice of medicine, and for authority to shift from the doctor's expertise to the patient's experience. Further support for the newfound resistance of patient narratives to a perceived 'medical colonialism' (Tallis 2004: 2) arose from feminist and queer theory, and from the emerging field of disability studies.

The literary genre of pathography – autobiographical accounts of illness, or memoirs by partners, children or caregivers of those suffering from illness – is, as Roger Luckhurst has noted, 'a distinctly contemporary form' (Luckhurst 2008: 128). Coming to prominence with the AIDS crisis of the late 1980s and early 1990s, it subsequently burgeoned to encompass other illness narratives. In the UK, it found particular expression in the 1990s in 'newspaper columns devoted to the progress of an illness' (Luckhurst 2008: 130). The rise of pathography can clearly be related to the shifts in the conception of narrative analyzed above. It acted at once to

focus attention on patient narrative and experience, to critique scientific biomedicine's concentration on disease rather than illness, and to protest the perceived distance and disengagement of medical professionals as well as broader institutional flaws and inequities. There are, nevertheless, other important aspects to pathography that are not encompassed in this description. John Wiltshire has astutely observed that pathography 'has a broader agenda than simply, like the postcolonial subject, to "write back" to the conquering imperialism of biomedicine' (Wiltshire 2000: 412–13). Rather, he focuses attention back on the pathography as illness narrative, noting that 'the raw material of pathography is illness, usually devastating or mortal illness', which involves 'the evacuation or stripping of meaning from both person and event' (Wiltshire 2000: 412–13).

Pathography differs from ordinary (auto)biography because its subject is not chosen: the pathographer often writes reluctantly and out of necessity. For the writer, then, the illness narrative is produced '[u]nder duress' and is shaped by 'contingency' (Wiltshire 2000: 414). For readers of pathographies, the narratives offer access to the dramas and dilemmas of life and death, which 'in our secular state we have now few other means of apprehending' (Wiltshire 2000: 15). For both writer and reader, then, pathography functions as the site of a limit experience, an encounter with (possible) death that engages powerful questions of consciousness, agency, and identity. Although Wiltshire notes that the narrative imperative of many pathographies 'is to make sense of this' in a 'process[s] of meaning-creation' (Wiltshire 2000: 412–13), it is also the case that pathographies often falter, fail in, or actively resist this endeavour at mastery.

Jackie Stacey's *Teratologies: A Cultural Study of Cancer* (1997) is a (self-)reflective contribution to a genre of pathography that was already well developed. It is, as Franziska Gygas has observed, 'both an autobiographical illness narrative and a theoretical exploration of the cultural constructions of cancer' (2009: 291). A British academic specializing in women's studies and cultural studies, Stacey consciously writes her cancer narrative in the tradition of US feminists Audre Lorde (1980) and Eve Sedgwick (1993), emphasizing that the personal is also the political; that the retelling of her own experience necessarily opens out to broader cultural concerns or, as she phrases it, 'the meanings attributed to cancer in today's changing health cultures' (Stacey 1997: 25). Stacey opens her narrative by declaring, like Wiltshire, that what most patient accounts of cancer share in common is an impulse towards mastery, the imparting of knowledge snatched from the brink of collapse:

If the person with cancer has lived to tell the tale, the story is often of a heroic struggle against adversity. Pitting life against death and drawing on all possible resources, the patient moves from victim to survivor and 'triumphs over the tragedy' that has unexpectedly threatened their

life.... The person who has faced death and yet still lives, who has recognised the inevitability of human mortality, now benefits from a new-found wisdom. Accepting the fragility of life itself, the cancer survivor sees things others are not brave enough to face (or so the story goes).  
(Stacey 1997: 1)

Arthur W. Frank promulgated a particularly influential version of the 'story' that Stacey recounts in his typology of illness narratives, *The Wounded Storyteller* (1995). Here, Frank classified illness narratives into three categories – 'restitution', 'chaos', and 'quest' – which are also suggestive of a journey towards mastery in the patient. Hydén accordingly notes that the problem with Frank's model is that it advances 'a meta-narrative of illness: from "chaos" to "quest"' (Hydén 1997: 54).

Against the closure and certainties that dominate the patient cancer stories that she turns to in her own illness, Stacey's narrative holds onto the 'chaos' experienced in illness. She places the desire for mastery that she encounters in illness narratives alongside the same impulse that she finds at work in both scientific medicine and self-help practices. In particular, Stacey makes clear that the prevailing rhetoric of control stands in painful opposition to the multiple, often contradictory, theories of cancer with which the sick person is confronted. Individual responsibility for health can be empowering, she acknowledges, but it can equally be overpowering, resulting in the patient's feeling confused and overwhelmed. Against the multiple narratives of certainty that surround cancer, which encompass the patient, the medical clinician, and the self-help manual, the theoretical sections of Stacey's book become, in the eloquent words of Gygas, 'exercises in searching and challenging, charged with uncertainty rather than mastery' (Gygas 2009: 298). Stacey's conclusion positions 'mystery' in opposition to 'mastery', and confronts biomedicine with the need to tolerate mystery as something other than 'an object to be known'; to more fully encounter that which resists meaning, and which is not predictable in outcome (Stacey 1997: 238). In her own autopathography, therefore, Stacey (re)orients theory away from definite answers and towards questioning; she thereby confronts contemporary medicine with a powerful contradiction between the rhetoric of (self-)mastery that it preaches, and the uncertainty if not outright confusion that can result in practice.

In what follows, I propose that Stacey's study is indicative of a possible route towards a more integrated approach to the literary in the medical humanities. First, the *form* of Stacey's study, which mixes autobiography and theory, indicates the potential for the field to engage with an expanded notion of literary genre, encompassing more fragmentary or mixed-media narrative modes. Hartman takes up this point, noting: 'more could be done in the medical humanities with different aspects of literature, not only its

narrative component' (Hartman 2004: 342). Within this volume, we can turn to Ian Williams' analysis of the graphic pathography, as well as the broader attention paid to art, music, and drama alongside literature, as productive examples of this kind of work. Stacey's dwelling upon, and within, the more chaotic and contingent aspects of her experience is also suggestive that there are dimensions of illness that do not readily conform to conventional narrative modes. In mixing literary modes, Stacey indicates that her cancer experience is elusive to expression; that a single literary form can go so far, but then a switch to an alternative genre is required. Returning to Hartman, he argues that the medical humanities should 'be sensitive also to nonnarrative, apparently inconsequential or lyrical moments, surprises in the narrator's mood and mode' (Hartman 2004: 343). Against a predominant emphasis on realist fiction and autobiography, Hartman indicates that we could productively also incorporate more poetic and experimental genres, as well as attending carefully to moments of narrative disjunction and discontinuity. Rather than subscribing to a dominant impulse towards meaning and control, we might then also benefit from what the literary can reveal to us about what it means to live in a condition of *uncertainty*.

Stacey's compelling critique of the impulse towards mastery across illness narratives and medical/alternative therapies also indicates that, in addressing what the literary can tell us about how we are potentially undone by illness, we might also reorient medicine itself. Kathryn Montgomery has recently examined the extent to which medicine is a discourse of mastery. In spite of its reliance on 'a well-stocked fund of scientific knowledge and its use of technology', Montgomery argues, medicine is 'not itself a science' but rather 'a practice: the care of sick people' (Montgomery 2006: 3). Montgomery's reorientation of medicine towards treatment places emphasis on how general rules – scientific principles or clinical guidelines – apply to the particular patient. In other words, medicine's core activity is one of 'interpretive practice', which renders it a 'still uncertain quest' and one characterized above all by 'contingency' (Montgomery 2006: 4–5). A more expansive sense of the literary might, then, potentially also open up a more integrated approach to literature in the medical humanities; one which enables us to address medicine's own inherent uncertainties, and the skills of interpretative reading that it accordingly requires of its practitioners.

Emerging at the same time as the medical humanities in the UK, the genre of pathography can be seen to share many of the same concerns: to refocus attention on the patient narrative, to voice experiences that are too often occluded from the medical account, and at times to challenge and contest biomedical practices. It is unsurprising, then, that the medical humanities have readily incorporated pathography into teaching curricula. Paul Crawford and Charley Baker accordingly privilege pathography over fictional narrative for medical professionals because of its focus on 'actual

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experiences as opposed to created, imagined experience' (Crawford and Baker 2009: 247). They are particularly concerned with psychiatric training and pathographies of mental illness can, they argue, provide insight into 'the traumatising experience of mental illness' and help the trainee practitioner to 'get a sense of what it might be like to be depressed, addicted to drugs or disrupted by psychosis' (Crawford and Baker 2009: 253-4). If the medical humanities have embraced the genre of pathography, then, it is valued primarily as a vehicle to mobilize the practitioner's empathetic understanding. I have suggested in this section, however, that pathography can be, and do, more than this. It can lead us beyond conventional narrative forms to more experimental, mixed-media modes and genres.

I do not wish to claim that these kinds of texts are a privileged mode for representing illness, which circulates across all forms of cultural production. There is, nevertheless, arguably something about such works – and about attending to disruptive and disconnected moments in more conventional accounts – that can open up important aspects of the patient experience. Pathography can also signal the ways in which illness often challenges – and reveals as illusory – discourses of mastery, whether they emerge from the patient, the doctor, or the self-help manual. In so doing, it signals a more integrated role for the literary in the medical humanities, which would be centrally concerned with the literary and the medical and inherently contingent modes. Shared affinities between the medical and the literary operate not only at an emotional level (how doctors feel), but also at an interpretive level (how doctors think). Rather than harnessing literature to an existing agenda, in which empathy is treated as yet another skill for doctors to master, we might therefore productively connect clinical diagnosis and literary reading as necessarily uncertain, yet essential, modes of interpretative practice.

### Arts in healthcare

I have so far examined major shifts in the conception of narrative prior to, and coincident with, the emergence of the medical humanities in the early 1990s, in order to trace the roots of the medical humanities from a specifically literary perspective. The establishment of the medical humanities as an identifiable field of study dates in the UK from the 1990s, however, and in the remainder of my chapter I accordingly turn to the 1990s and 2000s with the aim of outlining what I see as the main challenges for, and areas of potential within, the current field. In this section, I focus on the arts in healthcare movement. Fiona Hamilton further explores this movement within this volume, bringing a practitioner's perspective to bear on her literature and medicine case study. My own discussion identifies the arts in healthcare movement as one of significant potential, but also as a strand of the medical humanities that reveals one of its most formidable challenges. My closing section then goes on to examine the current shift towards a

critical medical humanities, and to ask how that development might potentially (re)shape the present field of study.

The medical humanities are broadly understood to encompass the burgeoning arts in healthcare movement, and the naming of the disciplinary field – its inherent privileging of medicine over health, and of the humanities over the arts – has accordingly become a vital subject of contention and debate. The arts in health movement has recently moved in the UK from what Macnaughton *et al.* describe as 'a small, local and poorly resourced movement fuelled by deeply committed artists, involved health-care professionals, and participants' (Macnaughton *et al.* 2005: 337) to a more diverse field, operating in a variety of healthcare contexts and with newly emergent areas of specialist expertise. Indeed, such has been the reported success of arts in healthcare initiatives that the Department of Health report to review arts in health in 2007 found that: 'arts and health initiatives are delivering real and measurable benefits across a wide range of priority areas for health' (Crown, 2007).

With regard to literature specifically, arts in health initiatives are focused on creative writing workshops delivered across a wide range of healthcare settings and to professionals as well as patients. There has also been significant activity around shared reading, emerging from the initiatives of the Reader Organisation in Liverpool, that have now spread nationwide. In spite of numerous endorsements of the field, however, a major challenge remains in defining exactly how the success of such initiatives might be measured or evaluated, and according to what criteria. In assessing arts in healthcare projects, Macnaughton *et al.* explain that practitioners typically accept it as unrealistic 'to aim at directly measurable health gain', because this usually entails 'locating some numerically assessable physical change' (Macnaughton *et al.* 2005: 335). Part of the problem, they point out, is that the success of arts in health projects is typically based in a diverse range of factors, which encompass not only the arts activity itself, but also the relationships between all of those involved in the project, how it is delivered, and the environment within which it is performed. To access evidence of all of these gains, practitioners often 'fall back on the voluntary testimony of participants themselves, which can readily be dismissed as "soft"' (Macnaughton *et al.* 2005: 336). The arts in health movement seems, therefore, to be caught in an intractable situation, which Macnaughton *et al.* summarize as follows:

Unless [the arts in health movement] produces an appropriate evidence base for its work it will not gain access to better sources of funding from the health sector, and because it does not have access to sufficient funding it is struggling to work up this evidence base. The bind tightens when arts and health projects attempt to approach evaluation of their work in a way that satisfies the health sector's view of what constitutes appropriate evidence.

(Macnaughton *et al.* 2005: 338)



In confronting this double bind, Macnaughton *et al.* recommend that the field adopt a robust approach, which would involve 'stak[ing] its claim to the research context in which it is operating' rather than 'trying to appease the research funding bodies by forcing the field into the straitjacket of a potential model of research' (Macnaughton *et al.* 2005: 338).

While I agree that it is vital to define and defend what is distinctive about research in the arts and humanities, I am also wary of a potential disciplinary entrenchment that further reinforces the divide between arts and sciences. If personal accounts and qualitative research studies are insufficient to convince funding bodies of the success of arts initiatives, creative and collaborative thinking is needed from both the humanities and medicine in order to formulate innovative criteria of evaluation. One area in which such conversations are currently taking place is the new brain-imaging technologies. These offer the potential to measure what happens in the brain when, for example, people write, read out, or respond to a poem, and therefore begin to bridge arts and humanities research and medical paradigms of evidence. At the same time, it is important that the conversation on brain imaging does not become one-sided, with scholars in the humanities simply absorbing medical technologies into their own research practice and accepting at face value the rhetoric of proof that surrounds them. This is a technology, after all, that produces images or representations that should themselves be interrogated aesthetically, culturally, socially, and historically, and with critical attention to how such images are read (Daston and Galison 1992). It is not only, then, that arts in health can play an additive role in medicine, enhancing healthcare environments and service provision; the arts and humanities can also intervene critically, as Sander L. Gilman has recently suggested, engaging with medical representations 'not to show their duplicity or truth but to reveal their function in their historical context' (Gilman 2011: 73). Here again, it seems, a more integrated potential for the humanities in relation to medicine might potentially be located.

This section has used the example of the arts in health movement in order to identify a major challenge posed to the medical humanities by questions of value, evidence, proof, and measurability. While endorsing the call by Macnaughton *et al.* for the arts and humanities to defend their own practices and methodologies, I also suggest that the medical humanities might offer a fruitful context for both the humanities and medicine to articulate what it is that they do, and to rethink how their respective areas of expertise might most productively intersect. In the following section, I examine the rise of the critical medical humanities in particular as a key forum for the furthering of such an agenda, focusing on its turn away from the treatment dynamic of practitioner-patient, around which our discussion has so far been focused, and towards a redefinition of the human in both individual and social terms. I will identify in my discussion two main works of recent British fiction that can be productively linked to the critical

medical humanities, namely Kazuo Ishiguro's *Never Let Me Go* (2005) and Ian McEwan's *Saturday* (2005).

### The rise of the critical medical humanities

In this section, I seek to propose an alternative mode by which the literary might be positioned in relation to contemporary medicine, by focusing on the emergence of the critical medical humanities. As the field shifts, its focus is moving away from the education of the medical practitioner and towards a more critical, analytical, and politicized account not only of the human, but also of a notably technologized biomedicine. In doing so, the field is establishing itself within a multi-disciplinary base, bringing to its engagement with the medical insights drawn from disciplines as diverse as philosophy, narrative and film theory, critical neuroscience, and medical anthropology. A first implication of this work that can be noted, then, is that it challenges thinking along disciplinary lines; a broad interdisciplinary perspective is needed, which in turn calls into question whether we can still speak of a specifically 'literary' perspective on the medical humanities. In what follows, I nevertheless analyze the critical medical humanities through examination of Kazuo Ishiguro's *Never Let Me Go* and Ian McEwan's *Saturday*, with a focus on biomedicine and the brain sciences. However, my discussion of the field has wider implications. It is also applicable to Patricia Norvillo-Corvalán's chapter within this section, which shows how the literary reinterpretation of myths has been used for the purposes of cultural and political critique. Within this critical analytical model, the medical humanities are not conceptualized in purely humanizing or humanistic terms.

I turn first to Patricia Waugh's astute analysis of what current literature might have to offer to science. In surveying contemporary fiction, Waugh notes that new developments in science have significantly invigorated the novel genre: 'the vocabularies, images and ideas' of recent scientific discoveries have, she argues, 'stimulated an important... "fantastic" turn in literature itself' (Waugh 1997: 158). What, then, might literary fiction offer to science in return? Waugh herself offers a decisive answer to this question, by positioning imaginative fiction as an important site for the exploration of ideas and for rethinking the familiar:

Possible worlds, the radically heterogeneous, the other, can most effectively disturb our settled modes of thought and unconscious prejudices when they are embodied, fleshed out, made available for recognition and empathy. Only when given such form can they linger on, continuing to disturb the familiar, leaving unresolved the implications of that disturbance.

(Waugh 1997: 158)

It is notable, then, that if Waugh turns specifically to the narrative form of the novel, it is not to conventionally realist texts that she looks, but to more experimental, imaginative, and fantastical works of fiction.

Written in 1997, Waugh's observations predate the publication of Ishiguro's *Never Let Me Go* by almost a decade. Nevertheless, her description is remarkably evocative in relation to Ishiguro's depiction of an alternative England of the 1990s, which uncannily mirrors our own reality in order to provoke unsettling questions concerning both the nature of the human, and contemporary scientific biomedicine and the institutions of care. It is, to adopt Waugh's terminology, through 'fleshing out' his 'possible world' with Kathy H. and the other clones that Ishiguro achieves the remarkable effects of the novel, as these embodied presences do indeed 'linger on' for readers after the novel's close, haunting and disturbing 'familiar' and 'settled' modes of thought. A particular strength of the novel form, in this context, lies in its capacity to enable us to encounter, through extended interior narrative, another mind and the world as it is constituted by that mind. As we read Kathy H's narrative, we are at once immersed in her story-world and distanced from it through defamiliarization, which works effectively in turn to give us compassion for her at the same time as we question critically the nature and limits of the human. This capacity of the novel to draw us in through recognition, while at the same time causing us to rethink our inherent assumptions, has been powerfully explored and articulated by contemporary narratological critics such as David Herman (2002, 2011) and Alan Palmer (2008), whose work on the narrative representation of consciousness, and in particular on the interaction of the fictional mind and the reader's mind, has proved valuable in reorienting the relation between medicine and literature.

In relation to contemporary biomedicine, Gabriele Griffin has noted that *Never Let Me Go* coalesces 'a number of different but interrelated biotechnological developments – cloning, organ harvesting, designer babies – into one set of fictional preoccupations' (Griffin 2009: 649). Rather than reflecting biotechnology faithfully, however, Ishiguro's novel deliberately marks its own departure from science. Griffin observes that this is achieved in the first instance through an explicit disinterest in how the science of cloning actually works; although Kathy and the other students relate various theories about their 'possibles' – the people from whom they have been cloned – these remain only stories, and the novel notably avoids the technical vocabulary that is usually associated with the science-fiction genre. More than this, however, Griffin observes that Ishiguro consciously embeds into his fiction 'a gap... between biotechnological developments and their representation' (Griffin 2009: 649). Thus, even as science begins to move towards the engineering of human tissue, rendering obsolete the need to rely on complete organs for transplantation, Ishiguro sets out in the opposite direction, imagining the cloning of people. The space that is thereby opened up enables Ishiguro to focus his

reader's attention not on the actuality of biomedical practice, but on the moral and ethical matters that it raises; in other words, his fiction provides a site for reflecting on, rather than for simply mirroring, contemporary scientific developments.

While Griffin's emphasis is on Ishiguro's engagement with biomedicine, I have argued elsewhere that he deploys the same strategy of defamiliarization to reflect on contemporary institutions of care (Whitehead 2011). The run-down and underfunded recovery centres that the donors of Ishiguro's novel inhabit represent a bleak reworking of the contemporary British landscape of privatized care homes and centres, which, in the words of Tony Judt, have 'reduced the quality of service to the minimum in order to increase profits and dividends' (Judt 2010: 114). The word which is placed under most pressure in the novel, and which takes on sinister overtones from the very opening page, is 'carer'. In *Never Let Me Go*, the reader learns that this seemingly innocuous word conceals the terrible reality that, within this alternative England, children are cloned, raised in isolation from other children, and on reaching adulthood have their organs harvested in a series of operations in order to treat human diseases. Again, although this clearly does not reflect historical actuality, we can recognize in it not only an established international trade in organ harvesting but also the scandal-hit care institutions of the UK, in which the word 'care' has too often concealed hidden histories of cruelty and abuse. Ishiguro's novel therefore holds up an uncanny, distorted mirror to British medical practices and institutions, providing readers with a space for reflection on a bureaucratized materialism that shadows our own reality and that exists in contiguity – if not in continuity – with our own social and political world. In this sense, then, *Never Let Me Go* intersects with and illuminates the more politicized dimensions of the critical medical humanities, which are concerned with how new medical technologies can negatively transform landscapes and processes of treatment, as well as commodifying the relation of care itself.

Ian McEwan's *Saturday* offers an alternative, although complementary, insight into the current field of the medical humanities. Although in many ways a straightforwardly realist novel, McEwan's narrative of a day in the life of Henry Perowne has nevertheless been defined by critics as experimental in standing at the forefront of the burgeoning genre of the neuronovel. Laura Salisbury has accordingly noted that if the novel has traditionally concerned itself with 'the penetration of another consciousness', McEwan's recent fiction has 'repeatedly offered up scientised reconfigurations of this moment of aesthetic sensibility' (Salisbury 2010: 884); while Dominic Head, commenting specifically on McEwan's reworking of the modernist stream of consciousness novel – the spanning of a day nodes both to James Joyce's *Ulysses* (1922) and to Virginia Woolf's *Mrs Dalloway* (1925) – observes that the novelist is 'trying to produce, perhaps, a diagnostic "slice of mind" novel – working towards the literary equivalent of a computed tomography (CT) scan – rather than a modernist "slice of life"

novel' (Head 2007: 192). What is immediately apparent, then, is that McEwan holds up for inspection the role and remit of the contemporary novel, suggesting that it can and should be responsive to changing scientific views of consciousness and cognition; literature, in other words, is inseparable from other disciplines, which thereby intersect with and inform each other.

My comments so far have suggested that McEwan is responsive to developments in cognitive science, seeking ways in which to embed them into narrative discourse. Yet, in line with the impetus of the critical medical humanities, critics have also indicated that there is a more reciprocal relation between the novel and neuroscience than this implies. Thus, Jonah Lehrer has positioned *Saturday* as the genesis of a new cultural movement, 'a new fourth culture, one that seeks to discover relationships between the humanities and the sciences' (Lehrer 2007: 196; original emphasis), while Susan Green affirms that the novel reflects 'the new momentum between the sciences and the humanities giving rise to the interdisciplinary study of the mind – cognitive science' (Green 2010: 58). If these claims are valid, then *Saturday* assumes particular significance in relation to a further strand of the critical medical humanities, which brings contemporary neuroscience into dialogue with a renewed turn to phenomenology in the work of philosophers such as Shaun Gallagher (2005) and Dan Zahavi (2008), together with narratological explorations of how we understand and interact with fictional minds by critics such as Herman, Palmer, and Monika Fludernik (1996).

Although it is beyond the scope of this chapter to produce an extended reading of *Saturday*, it might nevertheless be worth pausing over the novel's opening lines to ponder what they suggest about contemporary literature's 'penetration of another consciousness', to borrow Salisbury's phrase:

Some hours before dawn Henry Perowne, a neurosurgeon, wakes to find himself already in motion, pushing back the covers from a sitting position, and then rising to his feet. It's not clear to him when exactly he became conscious, nor does it seem relevant. He's never done such a thing before, but he isn't alarmed or even faintly surprised, for the movement is easy, and pleasurable in his limbs, and his legs and back feel unusually strong. He stands there, naked by the bed – he always sleeps naked – feeling his full height, aware of his wife's patient breathing and of the wintry bedroom air on his skin. That too is a pleasurable sensation. His bedside clock shows three forty. He has no idea what he's doing out of bed: he has no need to relieve himself, nor is he disturbed by a dream or some element of the day before, or even by the state of the world. It's as if, standing there, he's materialised out of nothing, fully formed, unencumbered.

(McEwan 2005: 3)

I noted in the previous section that the new brain-imaging technologies are proving fertile ground for the intersection of medicine and the humanities. In the opening sentence of his novel, McEwan establishes this connection as his neurosurgeon protagonist reflects on his own coming to consciousness. Returning to Head, we can say that McEwan is offering us 'the literary equivalent of a CT scan' (Head 2007: 192); if the scan can show us cognitive activity, however, the novel explores what it feels like – it gives us a crucial subjective dimension. In so doing, the passage notably takes on an unmistakable phenomenological aspect: firstly, Perowne's mind is necessarily embodied, so that any narrative of his cognition has to take into account, more or less consciously, his physical and sensory experiences; secondly, conscious or cognitive experience here follows the physical, or in the words of Gallagher, 'the body anticipates and sets the stage for consciousness' (Gallagher 2005: 2); and finally, embodied cognition entails that consciousness leads out to engagement with the world and with others: it is not, in other words, a solipsistic experience. The novel's opening also clearly gestures towards the narratological – Perowne's coming to consciousness is also the coming into being of his fictional mind. He has indeed, in this sense, 'materialised out of nothing, fully formed' for the reader on the page; but the reader is also left to question throughout the novel the precise form that is taken by this act of 'materialisation'. The following questions are accordingly central to McEwan's recent work of fiction: How exactly do we interact with the mind of Perowne? To what extent do we immerse ourselves in his storyworld? What is at stake in entering another's consciousness through the act of reading? In this sense, then, we can position *Saturday* as a novel that is highly resonant with the critical medical humanities, not least in its self-reflexive intermingling of narrative, scientific, and philosophical accounts of consciousness and cognition.

This section has offered an approach to the literary which stands in deliberate contrast to the mode of reading often regarded as characteristic of the medical humanities. I have focused on two novels, both of which demonstrate aspects of formal experimentation. My discussion of Ishiguro's *Never Let Me Go* draws on Waugh to emphasize that more fantastic works of fiction can allow space, in her terms, for 'cognitive estrangement without the burden of scientific proof' (Waugh 1997: 159). I have suggested that within the alternative worlds embodied in imaginative fiction, ideas are rendered strange in ways that can open up space for reflection and critique, or can even potentially, to return to Waugh, 'actually create that for which there was previously no concept or idea' (Waugh 1997: 159). In Ishiguro, this space of reflection opens up questions, central to the critical medical humanities, concerning the nature and limits of the human, as well as the material and political effects of biomedical technologization. My reading of McEwan's *Saturday* indicated a further area of current research, namely the interdisciplinary study of the theory of mind. Not only does this work enrich the form of the novel itself, but the act of

reading – our pleasurable interaction with fictional minds – can also stimulate in turn important questions of cognition and of empathy.

### Conclusion

In this chapter I have argued that the first wave of the medical humanities, here encapsulated by Charon's narrative medicine, has developed a distinctive but restricted approach to literature, both in terms of the canon of texts – predominantly realist fiction and autobiography – that it integrates into teaching curricula; and in its hermeneutic approach, which espouses a somewhat traditional attitude to the humanities as humanizing, and emphasizes a model of reader empathy leading directly to compassionate action. I have sought to open up a number of approaches by which this conception of the literary might usefully be expanded, although it is intended that my suggestions should be read as indicative rather than exhaustive in nature. Following Hartman, I have indicated that mixed media, fragmentary, and experimental texts also provide a productive mode for examining how experiences of illness and pain might be represented in literary form. I have proposed that literature can fruitfully intersect with medicine in opening up the uncertain and contingent; in this sense, drawing on Montgomery, it might help to reorient medical practice itself away from the rhetoric of scientific certainty and towards interpretive reading and thinking. Turning to more recent developments in the field, I focused first on the arts in healthcare movement, which has launched a range of Creative Writing initiatives across a variety of institutional settings, and has been widely recognized as beneficial to health and well-being. However, initiatives have notably struggled to provide an evidence base to measure value in a way that is acceptable to funding bodies, and I have argued that both creative and collaborative thinking is needed in this area. I ended by examining the second wave of the medical humanities, namely the critical medical humanities, which are explicitly concerned to move away from a focus on questions of practitioner pedagogy and training, and to situate themselves instead in a more critical and analytical relation to medicine. If this development in the field is indicative of its future direction, then we will see a more politicized, a more theorized, and a more radically interdisciplinary field coming into view.

In closing, I turn to Gilman's recent diagnosis of the current state of the humanities. In these straitened financial times, he argues, both creative and constructive thinking are required within the academy. 'We need to think more intensely', he observes, 'how our wider theoretical expertise can, indeed must, mesh with alternative forms for the presentation of humanities knowledge and experience'. Gilman contends that the potential for such thinking already exists, albeit 'still in a tentative way', in the field of the medical humanities (Gilman 2004: 387). Gilman's rapid sketch of the field provides an accurate summary of its priorities in the first wave

of activity; he notes that it has embraced narrative 'as an inherent component of pedagogy', that the 'act of reading' has become a mode through which 'young physicians are trained', and that it has claimed 'the tools of interpretation' as 'inherent to the [medical] profession itself' (2004: 386). My chapter has sought to build on these 'tentative' beginnings, and to identify potential areas for future work, although this has necessarily entailed moving beyond the literary to some degree. To some extent, I share Gilman's optimistic sense of what might be possible over the next decade or so. 'Times of stress', he points out, 'should enable us to rethink in ways that times of excess do not'. He crucially adds, however: 'Here the role of the humanities should be paramount' (Gilman 2004: 389). To date, the medical humanities have tended to be dominated by the needs and priorities of medicine itself. It remains to be seen whether a more truly collaborative enterprise can grow out of the activity in the critical medical humanities, creating a field that expands beyond the more immediate concerns of training and pedagogy to explore the multiple and complex ways in which medicine and the humanities might interact critically and analytically with one another.

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### Notes

- 1 Although I have started my narrative with Charon, the texts which first paid extended attention to narrative medicine were, in the US, Montgomery Hunter (1991) and in the UK Greenhalgh and Hurwitz (1998).
- 2 This connection is not purely literary. On the visual aspects of Balint, Berger and Mohr, see Ludmilla Jordanova's chapter within this volume.

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