MITA BANERJEE

Medical Humanities in American Studies

Life Writing, Narrative Medicine, and the Power of Autobiography

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Preface

Developments in biomedicine have changed the ways in which we conceptualize what it means to be human: From developments in brain research to reproductive technologies, our ways of being in the world and of coming into the world have changed more fundamentally than we would ever have been able to imagine. Yet, in tandem with these developments in biomedicine, we are now faced with forms of decision-making more complex than we could ever have imagined. Nothing, it would seem, is completely outside our reach, and yet, the choices make our being in the world at once easier and much more difficult. Genetic research may now have found a gene which may be involved in the development of Alzheimer's disease, detecting this gene may be possible even in childhood: "Individuals carrying a particular variant of the apolipoprotein E gene, probably have a higher risk of falling ill with Alzheimer's Disease later in life. Now scientists have found that even in young children, this allele can be related to changes in brain development and cognitive performance" ("Alzheimerdemenz: Belastendes Erbe" 10; my trans.).

Yet, how will the knowledge of having such a genetic predisposition affect the lives of the people whose future thus seems almost mapped out? Under what circumstances do we want to know what our genetic future may hold, and under what conditions would we prefer not to know? And by what compass do we gauge our route in this labyrinth of decision-making made possible by advances in biomedicine? One of the assumptions from which this book proceeds is that in this labyrinth of complex choices, it is to forms of life writing (biographies, autobiographies, blogs, patient narratives) that we may turn for orientation. What these life writing narratives reveal, then, is what course a life has taken *after* a certain decision was made, a decision made possible by advances in biomedicine. This, I propose in this book, is the need for bringing together, for creating a dialogue between, life writing and life sciences: The life sciences may provide us with a way of creating, of enhancing, and of prolonging life; yet, life writing asks, how do we live with these choices? How does the possibility of being able to make these choices change our lives themselves?

Developments in modern biomedicine thus confront us with decisions which we may often feel ill-equipped to make, decisions so existential to our lives or the lives of our loved ones that they seem impossible to make. Such decision-making and the conditions under which they are made, has been the subject of bioethics. Bioethics, in turn, has a strong narrative component. To the extent that the humanities engage with developments in modern medicine, conversely, they too have narratives to offer. If there is a narrative turn in medicine and bioethics, then, there has also been, at the same historical moment, a material turn in the humanities. Drawing on the work of Antonio Damasio[1], among many others, John Paul Eakin has cautioned that the humanities have separated the body from the mind, and the mind from the brain, for too long; that the necessity of overcoming the Cartesian dualism affects not only the life sciences but the humanities as well.

This book thus proceeds from a threefold assumption. First, it argues that overcoming the Cartesian split between body and mind may also require the emergence of a dialogue between life sciences and the humanities. Second, it locates in life writing as a genre a potential link between life sciences and the humanities, precisely because forms of life writing may describe the consequences, on the level of lived experience,[2] of biomedical decisions taken. Third, it locates in the history of the present moment a convergence between life sciences and the humanities, where each of these fields, after a century of separate developments, may be newly attuned to what the other has to offer. As Wolf Singer has recently argued,

> The creative process is the same for science and art. In science, the cognitive process begins with generating hypotheses. [These hypotheses] are first conceived through intuition, often based on criteria of aesthetic consistency which cannot be rationalized. Apparently, scientists are looking for similar criteria as artists: for coherence and closure. Many things in science are dominated by aesthetics. . . . The artist proceeds in a very similar manner; only the material which he handles is different. The artist, too, creates an image of the world as he interprets it, thus re-

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[1] I am indebted to Alfred Hornung for this line of argument.

[2] I am grateful to Norbert Paul for this idea.

> maining within a particular descriptive system, he creates new realities, new interpretations [.] The scientist does the same when he creates a model for what can be experienced. Of course, the assumption and the craftsmanship are different, but the underlying processes, it seems to me, are highly similar for science and for art. (80; my trans.)

If indeed, as Singer argues, both the artist and the scientist develop models of the world, then it would seem more urgent than ever at the beginning of the twenty-first century to create a dialogue between these perspectives. Each in its turn may point to the shortcomings of the other. What is so intriguing about Singer's acknowledgment of the "scientific" work of the artist, then, is the absence of a hierarchy between life sciences and art: If indeed there is to be a dialogue between the two, both must meet on par.

Yet art, it may be argued, is different from life writing; in order to be art, it involves the aestheticization of lived experience. At the same time, life writing research has stressed the constructedness of life writing; any autobiography, life writing researchers have argued, also involves a degree of fictionality, of a construction of the self. It is for this reason that I argue that Singer's vision for abolishing the clear-cut distinction, even opposition, between the life sciences and the humanities may involve the inclusion not only of art, but also of forms of life writing.

At the same time, humanities researchers may feel that entering such a dialogue on Singer's terms may be a form of selling out; in order to maintain or regain their self-confidence at a time when many have declared the humanities obsolete, why should the humanities need the recognition of brain scientists like Singer? I believe that such fear of selling out may be unnecessary; even as the humanities must of course generate their self-confidence from within themselves, the willingness of the life sciences to engage with the intrinsic logic of the humanities – vastly different from their own – may nonetheless be beneficial.

Finally, I believe that the terrain whose surface this book can merely scratch is expanding by the minute: Because of the speed at which new developments in the life sciences occur, new ethical dilemmas, new forms of decision-making arise every second of our lives. It seems imperative, then, that the humanities enter into this dialogue, providing their own compasses and cues for decision-making in the era of biomedicine. Art, in its turn, has long taken on this challenge. If indeed art (literature, poetry, painting, photography, film) can be conceived as a form of theory in practice, then, art has long functioned as a compass in the labyrinth of biomedical and bioethical decision-making. To the extent that the humanities include such art forms into their canon, then – from “crip poetry” (Bartlett 16) to ballet –, they, too, enter into the dialogue.

Art, then, may be useful not just in the training of future doctors, but also in guiding us through the ever more complex processes of medical decision-making. To explore these processes, then, does not concern bioethics alone, but it must also centrally concern the humanities. Even as the examples I draw from in this book are taken from (transnational) American culture, my argument about the reach and relevance of the humanities may also be applicable to other disciplines within the humanities as well.

Life writing and life writing research thus converges with, for instance, the sociology of medicine in asking how biomedical developments are understood in the public sphere, how they are translated into social realities. Yet, life writing and art also comment in their own language, on these developments, gauging their desirability; they do not only describe but seek to intervene. In so doing, they also inquire into the reach – the *Deutungsmacht* – which developments in the life sciences have over our lives and the ways we defined them. As Michael Hagner puts it, “Here, too, scientists must be careful not to assume a perspective which is all too organ-centered, drawing conclusions about invariable characteristics of people solely on the basis of characteristics of the brain or its activity patterns” (33; my trans.). This necessity, of course, has been stressed by both brain researchers and geneticists; the field of epigenetics and research into gene expression has stressed the need for multifactorial approaches. What is at stake, then, is not (only) what brain research finds out about the workings of the human mind, but what the consequences (social, cultural, economic) of such findings are. It may be art and forms of life writing, then, which may help us deal with such consequences.

I believe that the discussion around the development of new drugs counteracting some of the effects of Down Syndrome and a photographic exhibit portraying persons with Down Syndrome may serve as an example to describe a canvas of disciplinary and artistic responses. New developments in biomedicine, as in Alberto Costa’s work with neurotransmitters such as the receptor NMDA, make possible the development of new drugs targeting neurotransmitters, hence making it possible to counteract learning difficulties; photographic exhibits such as Sigga Ella's "First and Foremost I Am" (2014) stress that regardless of such drugs, we as a society must strive to include all differences, whatever they may be; and Hille Haker, drawing on bioethical debates and coming from the field of theological ethics, stresses that the argument that such drugs, once they have been developed, be *withheld* from persons with Down Syndrome is itself highly problematic. As Haker observes,

> For some, those concerned are only impaired because they lack sufficient social support. From this perspective, not the people living with Down Syndrome have to change, but society has to change in order to provide a place and possibility of belonging for all people. Others see disability as a physical, psychological or cognitive impairment, which is rooted in biological causes, which in principle can be researched and treated. Often, these positions seem mutually exclusive. But this is not the case: In fact, what discussions should revolve around/focus on is the compatibility of social and medical arguments. (77; my trans.)

Medical support, Haker suggests, is a form of social support as well. As Haker goes on to say, "Possibly, those who oppose medical research, end up preventing the individual possibilities of experience for which they are in fact fighting. For medical support is also a form of social aid" (77; my trans.).

The photographs are inseparable, then, from a specific moment in the history of science: a moment in which it now seems possible to make some of the symptoms of Down Syndrome invisible. Whether or not the persons concerned should take the pill or not, at first glance, seems to be a bioethical decision; it is a process of decision-making, however, which art – in this case, photography – has also begun to enter. It is in this sense, then, that the photographs engage in a form of life writing; they make visible the lives behind the "condition," lives which can never be fully captured by a given diagnosis. If the life sciences offer to us a new choice – the possibility of making the symptoms of Down Syndrome invisible – then, the photographs help us navigate the process of decision-making.

The effects of these drugs on the quality of life, but also the ensuing biography of the individual, however, can also be explored through forms of life writing. Thus, in her autobiography *Thinking in Pictures* (1995), Temple Grandin stresses that she has come to be a "believer in biochemistry" (123). As Grandin recalls about her life as a young scientist,

> I went to every doctor in town, but they found no physical cause for the headache that accompanied my anxiety. . . . Medical science was failing me, and I just took each day at a time and tried to get through it. . . . It was then that I turned to biochemistry to help me with the anxiety disorder I had lived with my whole adult life. . . . Six months prior to my eye surgery, I had read an article titled "The Promise of Biological Psychiatry" in the February 1981 issue of *Psychology Today*. (*Thinking in Pictures* 124-25)

What is so striking about this account is that Grandin's experience, and the stance she decides to take, anticipates current debates, at the beginning of the twenty-first century, about the difference, and possible points of intersection, between behavioral psychology and biological psychology (Flor 2016). Faced with the fact that behavioral psychology was unable to help her deal with her panic attacks, Grandin proceeds to do research; her solution, then, anticipates a development – a balance or fusion between behavioral therapy and neuropsychiatry – which has only taken hold at the beginning of the twenty-first century. It is in this sense, then, that it would be highly reductionist to reduce Grandin's narrative to the level of a patient account; it is also an account of the history of science, and it is a book written by a woman who earned a degree in psychology before going on to do her PhD in animal science.

My claim throughout this book is that such accounts are much more than *Betroffenenperspektiven* or patient accounts. In fact, one of the goals of this study is to inquire into the perspectival complexity which has been hidden or obfuscated by the term "*Betroffenenperspektive*." Recent studies in aging research, as in longevity studies and centenarian studies, have drawn attention to the need for extended interviews, for supplementing quantitative through qualitative analyses. In this revision, then, life writing narratives may prove powerful documents for upsetting the dichotomy, and the erstwhile hierarchy, between medical experts and laymen and -women.

What does this mean for our methodological practice? It means that we may come to contextualize cultural texts (literature, art, life writing) not just in historical terms, but also in terms of this history of science. Cultural texts respond to and are shaped not just by historical conditions and legal parameters, but also by new developments in the life sciences. If our lives are reshaped by new developments in the life sciences, then life writing can no longer be separated from life science research.

New developments in the field of biomedicine, this book sets out to argue, make an interdisciplinary canvas of approaches more urgent and more relevant than ever before. It is in this context and out of this sense of urgency that new fields have emerged such as medical humanities and narrative medicine. It is these fields and their “reverse relevance” for a potential redefinition of the humanities that the following chapters set out to explore.

1 Introduction

1.1 Life Sciences and Life Writing

This study begins with a simple question: If the humanities have "exported" some of their methodologies in order to create the field of "medical humanities," what happens to the humanities in the process? My aim in the following chapters is to inquire whether this export of techniques of literary and cultural analysis has any bearing or effect on the field in which these methodologies originate. In other words, are the humanities to remain the same regardless of this "exporting" of some of their methodologies to other fields such as medicine, or is there a sense in which they, too, may benefit from this export? What would happen, then, if the humanities were to set out to "re-import" the very field they had once exported? The central premise of this book is that the emergence of fields such as medical humanities and narrative medicine may have created a space in which a dialogue between the life sciences and the humanities can emerge. This dialogue, in turn, may profoundly alter or at least affect both the humanities and the life sciences. The fields of medical humanities and narrative medicine can hence be read as disciplinary "contact zones" (Pratt 33) between the humanities and the life sciences, and they may have repercussions for the fields which they originally set out to fuse.

This book starts out from a simple premise: that there is a need for a critical and sustained dialogue between the life sciences as a field of both practice and knowledge production, and the genre of life writing as it conveys a deeply personalized experience of human fallibility, vulnerability and ephemerality. It argues that the emergence of medical humanities as a field, as well as approaches such as narrative medicine, have both challenged and enriched the humanities. Conversely, the humanities, through medical humanities and by being asked to be of service to medical practice, have themselves been infused with a new sense of their own relevance, a relevance that may also be deeply ambivalent and often problematic. This book argues that to resist such forms of utilitarianism, to dismiss the question of relevance in and of itself, may also be a dead end for the humanities. What may matter, beyond such mutual suspicion, may be a careful analysis of the agendas of the humanities and of medical humanities, respectively.

Yet, it is also crucial to note that the humanities, particularly in and through the field of life writing research, have been tremendously enriched by new materials which they may previously have construed as rather marginal to their own endeavor. This book suggests that the inclusion of autobiographies such as Tito Mukhopadhyay's *Beyond the Silence*, Michael J. Fox's *Lucky Man* and Jason Kingsley's and Mitchell Levitz's co-written autobiography *Count Us In* may provide a challenge and stimulus for American Studies research in particular, since they force us to reconsider notions of authorship and of collaborative life writing, as well as to rethink the relationship between race, class, gender and sexuality on the one hand and disability on the other.

The agenda for this book is hence threefold. First, it explores the genre of life writing as a textual continuum in which traditional autobiography, biography and a host of other textual forms related to the course – and the meaning – of human life intersect with other forms of testimony and the idea of "bearing witness." Second, the following chapters explore the intersection between life sciences and life writing by arguing that life writing as a genre is particularly suited for opening up the humanities to other forms of research. This openness towards interdisciplinary cooperation which I locate, with Alfred Hornung, in life writing research is based on two aspects inherent in life writing as a genre. First, life writing research starts out from a highly open and extensive form of textuality; at its most extreme, it conflates the oral and the written, "reading," for instance, dance performances as forms of life writing. According to Hornung,

> Auto/biographical narratives display an ever-increasing range of media in which lives or parts of lives are presented: print media, performance, film and video, radio and tapes, or the Internet. Many autobiographies combine different media for intermedial effects, such as the inclusion of photography into texts, voice and music on the radio or tapes, sound and images in filmic auto/biography, or music and dance in self-performances. Autobiographical multi-media performances dissolve the boundaries between genres and technologies of signification. (xii)

Second, the relationship of life writing to the depiction of "life itself" (Rose 40) lends itself in a particular manner to a cooperation with the life sciences.[1] As Hornung goes on to suggest, there are many ways in which "autobiographical narratives mediate between different disciplines of the humanities, the social and natural sciences, and medicine" (xii). Arguably, the life sciences, too, create narratives of human life even if the status of these narratives has been conceived of in vastly different terms, resulting in the fact that these narratives have been said to have supra-narrative status.

The very title of this book may thus, in fact, be a paradox: What would it mean to bring (medical) humanities back to the humanities, as a sort of re-import in both methodological and institutional terms? My point is that medical humanities can be said to instrumentalize, to utilize the humanities as an import or sideline – if a significant sideline – to the training of medical doctors. According to the definition of medical humanities issued by the League of European Research Universities (LERU),

> [the] "medical humanities" include an interdisciplinary field of humanities, social science and the arts, and provide insight into the human condition, suffering, personhood, our responsibility towards each other as well as how social conditions and social institutions influence health and wellbeing and the effects of medical care. They also offer a historical perspective on medical practice. Attention to literature and the arts help to develop and nurture skills of observation, analysis, empathy, and self-reflection – skills that are essential for a humane medical care. (7)

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[1] It may be argued in terms of a cautionary note that there is a danger of life writing research going imperial here if life writing research claims for itself all these forms and genres traditionally located in other disciplines as, for instance, performance studies. Even as I acknowledge the risk of any approach going imperial by universalizing itself and, in the process, swallowing up all other disciplines, I would conceive of the link between life writing and other fields within the humanities in terms of complementarity rather than mutual exclusiveness. Thus, a dance performance can be explored both through the lens of life writing research and performance studies.

In this context, the humanities are inflected in a particular way. First, a variety of artistic media and genres are grouped together, and used in the didactics of medicine owing to their ability to "help to develop and nurture skills of observation, analysis, empathy and self-reflection." Here, the reception, the "reading" of "literature and the arts" is itself seen as a practice conducive to a more humane medical practice; the skills gained from the reading of literature, for instance, can be transferred, this approach holds, to medical practice. What this definition does not address, on the other hand, is the idea of creative writing or of drawing, the practice of self-reflection through creative expression which other methodologies, such as narrative medicine as well as the Swiss concept of "Menschenmedizin" have addressed (Hess and Hess-Cabalzar, *Menschenmedizin*).

What has been stressed in medical humanities approaches, then, is the advantage of "importing" the humanities into medicine, especially the didactics of medicine. In this study, then, I am interested in what may be the other side of this process. What happens if these differently inflected humanities are in their turn imported back, or "re-imported" into the humanities? What if we were to consider not the role of "medical humanities" for the practice or medicine, but for the practice of the humanities? In particular, the reinfusion of the humanities with medical humanities may lead us to reconsider some of the categories which the history of literary theory may have caused us to jettison, or to consider these categories in a different light. This may be true, above all, of the category of experience, as I will elaborate in the chapters that follow. What may be at stake here, then, is the difference between material and metaphor. In a given narrative, metaphors may be used to convey a certain illness, disability, or form of physical change; this metaphor can then be discussed, within the field of medicine or medical training, in a medical classroom and can thus serve to enhance processes of empathy on the part of doctors or medical students, with the patient in the (autobiographical or fictional) patient narrative. In so doing, as the LERU definition of medical humanities has suggested, the study of this literary or autobiographical narrative can help change the face of medicine. What, then, if this same narrative were to be reimported into a humanities classroom or re-inserted into a humanities research context? I believe that at its most fruitful, it would carry with it notions about the practice, both social and material, of medicine; in this reimported form, then, the metaphor could be read not only for its narrative but also its "practical" potential. There is, I am well aware, the danger of reductionism here; the humanities, in a line of reasoning that has by now become familiar, are reduced to the "use value" they may have for other disciplines, particularly the social sciences or, in this case, medicine. Yet, I believe that there may be qualities inherent in the concept of "application" or "applicability" which go beyond a reductionist utilitarianism. At the heart of the reimport of medical humanities into the humanities, or into fields such as American Studies specifically, there is a dialogue between the humanities and the practice of medicine. It is this dialogue with which this book will be concerned.

The key point, then, and the telos of medical humanities may be in medical practitioners and humanities scholars reading the same texts, and reading them in dialogue with each other and with each other's readings of these texts.[2] For this may be a pitfall inherent in the logic of utilitarianism. If illness narratives (autobiographies, paintings, music, poetry) are taken from the realm of the humanities to be used in medical classrooms, these narratives are often decontextualized: they become case studies of particular illnesses and they are used, of course, not for the purpose of eliciting aspects about literary theory or the history of autobiography (as I will argue in my discussion of Tito Mukhopadhyay's *The Mind Tree* in Chapter 2), but they are used as patient narratives and are hence reduced to the dimension of illness, even as they broaden the scope of the complexity of illness experience and its connection to the individual life of the patient. What would it mean for the same text to be read within and outside this context of case history and illness narrative? What if, for instance, Michael J. Fox's *Lucky Man* was to be read as an actor's autobiography and not a story about Parkinson's Disease at all? My aim in this study is to explore the potential of such alternate contextualizations of one and the same text. What emerges from this idea, then, is to inquire not just into the logic of a particular text but also and especially into the framework which we read it in. To reimport medical humanities (back) into the humanities may thus open up one more layer of meaning, and it may cause us to reconsider the question of relevance in a different light. What medical

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[2] I am indebted to Alfred Hornung for this point.

humanities as a field may imply is also a note of caution, a call on the humanities not to shy away, automatically and on principle, from some degree of utilitarianism. Yet, what is needed, I believe, is to carefully discuss the terms on which the "import" of the humanities into medicine takes place: What would it mean, molecular biologist Ralf Dahm has asked, to know that Monet's style of painting did not simply change because his eyesight was affected by illness but that in changing his painting style, he also changed the history of modern art (324)? What would it mean, in other words, to read Monet's account of his illness not only as an illness narrative and a form of coping with a lack of capability, but also in terms of the history of art? As Dahm writes,

> For artists whose eye conditions were not diagnosed precisely, it is difficult to judge in retrospect if or how their vision, their individual perception and thus their way of painting were affected by possible changes in their visual apparatus. For some painters, however, we can say with certainty that they were suffering from eye conditions. Their symptoms were documented by physicians, friends or by themselves. On this basis, it is possible to assess with relative reliability the impact of a change in vision on particular works of art. [Two] artists in particular form the basis of this article, artists whose eye diseases became manifest in their work: Claude Degas, who, in his last years, developed severe cataracts, and Edgar Degas, who suffered from macular degeneration. (324; my trans.)

To be sure, it could be argued that if illness narrative (or here, illness painting) has a place in medical classrooms, art history does not. Yet, there may be a key dimension in insisting both on the narrative as "case study" and on the context which, in the humanities, this narrative is accompanied by. In this larger framework, "coping" would take on an entirely different meaning: in "coping" with his illness, Monet changed the course which modern painting would take, revealing the complex interrelation between life writing (his change in painting style as a response to the changed capability of his body, or specifically his eyes), and artistic creation. In this interrelation, Monet the painter is not just Monet the patient, just as Tito Mukhopadhyay, I will argue in Chapter 2, is a literary author and not just an autistic writer. To insist on the relevance of art history also for medical humanities in "reading" Monet's painting, then, would be not to insist on or exaggerate the detailed knowledge and minute details of the humanities, to simply resist their "use value" for medical training, but to put Monet's "patient narrative" into a different perspective in which the painter's experience may be different from the patient's. I believe that it is only through this importing not just of the narrative but of its context that medical humanities can live up to their full potential. At the same time, and conversely, of course, the humanities may need to include not just Monet the painter – dismissing any reference to his illness or failing eyesight – but also Monet the patient. Only by so doing, do they stop reducing identity to the ideational aspects of a person's life, disregarding or dismissing the mooring of this identity in a material body as either inconsequential or trivial.

At the same time, the concept of "life writing" as I am using it in discussing the intersection between life writing and life sciences may require some explanation. The texts discussed in the first part of this book, from Chapters 2 to 7 – texts such as Tito Mukhopadhyay's *Beyond the Silence* (2000), or Michael J. Fox's *Lucky Man* (2002) – closely correspond to life writing in the form of written autobiographies by a single author. While some of these autobiographies already strain the limits of the concept of autobiography as such – Mukhopadhyay includes poems into his autobiographical account, Temple Grandin's *Thinking in Pictures* (1995) can also be read as a scientific discussion of the discipline of animal studies –, they can nevertheless still be subsumed under the label of "autobiography." The texts discussed in the second part of this study, on the other hand, point to an understanding of "life writing" which, paradoxically, goes beyond the written document. Rather, these texts define life writing, as Marlene Kadar has done in *Tracing the Autobiographical*, in the sense of testimony, or of performance. Moreover, they are forms of life writing not by an individual, but rather by a collective, a collective often haunted by trauma and histories of oppression. The second part of this book also addresses the question of what Alondra Nelson has called "medical discrimination." If the life sciences have disregarded the human rights of entire communities, such as the rights of the Marshall Islanders subjected to radiation through nuclear testing in the Pacific, how can this infringement of human rights also be accounted for by definitions of ethnic communities ingrained in the social spheres in which life scientists are located? In this sense, Chapters 8 through 10 address the relationship between collective trauma, communal forms of life writing, indigenous rights and environmental justice. By the same token, I am also interested in the question of whether these narratives – documentary films such as Adam Horowitz's film *Nuclear Savage* (2011), for instance – are commonly included into discussions of medical humanities. To the extent that these narratives are not included into medical humanities discussions, but are rather subsumed under indigenous rights discussions, I would argue, we risk perpetuating the practices of medical racism which caused illness and death in the first place. One of the issues that this study tries to address, then, is whether there has been implicit in the concept of medical humanities a certain "color-blindness," the idea that illness narratives convey, first and foremost, the experience of illness, regardless of the social, cultural or racial location of the speaking subject. Conversely, especially the texts discussed in the second part of this book stress the fact that these locations are by no means secondary to the experience of illness, but are in fact central to it. At the same time, this second part of my study is hence concerned not only with the intersection between medical racism and collective trauma, but also with forms of healing and reconciliation.

At the same time, the concept of life writing, especially as it can be seen as being in conversation with the life sciences, questions the very dichotomy between biography and autobiography.[3] This is a difference to which I will return in many of the chapters that follow. While the conflation of the two terms, as Thomas Couser has powerfully argued, can be problematic in many different ways, they may nevertheless be powerful in calling for, for instance, the rights of individuals who as yet may not have full access to channels in which they can represent themselves. As Couser writes in *Vulnerable Subjects: Ethics and Life Writing* (2004), "I am especially concerned here with the representation of subjects who are vulnerable to misrepresentation or betrayal because of some disadvantaged condition, particularly certain kinds of disability" (7).

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[3] As Couser puts it, "all autobiography is also in part biography" (Couser, *Vulnerable Subjects* 6).

1.2 Medical Humanities and American Studies

If medical humanities and the re-importation of medical humanities into the humanities is one of the aspects which this book sets out to explore, the notion of "American Studies" is the second one. What does it mean to reintroduce medical humanities not just to the humanities but to American Studies specifically? What is "American" about medical humanities? Or, on yet another level, what do American Studies have to offer to medical humanities? If indeed medical humanities are re-imported into American Studies, what is the specific ground which American Studies as a discipline would provide for this re-importation? In this context, I am interested in two aspects in particular. First, American Studies since their inception have always been a particularly interdisciplinary field. For this very reason, they may provide a particularly fertile ground for the inclusion of life writing research, which is itself interdisciplinary as it combines oral and written accounts, dialogues between historical records and autobiographical narratives, witness accounts and testimonies. It is the idea of "bearing witness" which informs many of the narratives I will discuss in the chapters that follow. In this context, one aspect which I will try to explore is the relationship between medical humanities on the one hand and life writing research on the other. Seen from the perspective of the humanities, much might indeed be gained from the exploration of this link: If medical humanities often dismiss or fail to take into account the specific genres from which a particular narrative is drawn, life writing research may provide an entry point from which to reconsider the notion of genre. Like the category of patient narrative, life writing research is concerned with the notion of lived experience, yet, unlike the majority of medical humanities research perhaps, it is nonetheless concerned with the question of genre, a concern which is, of course, linked to its location within the humanities. The fruitfulness of life writing research, then, is that it is at the same time aware of genre conventions and cultural, historical and political context *and* does not shy away from transcending this context. So what does life writing research have to offer to medical humanities, if the question of genre recedes into the background and if a particular narrative is read as an account of a specific illness, such as Michael J. Fox's account of his Parkinson's Disease? Nonetheless, life writing research can fruitfully complement medical humanities research by reintroducing the notion of genre. What does it mean, as Shapiro has asked, to take into account the expectations, the moorings and the trappings of a particular genre when it comes to telling a particular story? In what way is this story itself inflected by genre conventions? To read life writing into medical humanities and vice versa may hence itself be a crucial endeavor, perhaps, which will be key to the developments of both these fields of research, and of practice.

Yet, what is the role of American Studies in this context? If American Studies has been interdisciplinary from the beginning, it has also been transnational if less explicitly so. There is a profound interconnection, in the texts I will discuss, between what Shelley Fisher Fishkin has called the "transnational turn" of American Studies ("Crossroads in Cultures") and the cultural contexts from which these life writing narratives are drawn. In fact, each of them inflects the idea of "Americanness" differently. Tito Mukhopadhyay describes, in *The Mind Tree*, the fact that with his mother he has migrated from India to the U.S., his mother opening a school for autistic children in California. Yet, his narrative resists an emplotment and a teleology where the U.S. is always-already more enlightened than India when it comes to disability: instead, he is careful to describe his Indian doctor's key influence on his development. Nonetheless, there is a sense in which a certain teleology – the telos of medical humanities as an American telos –, may nonetheless undergird Tito Mukhopadhyay's narrative. What is at stake, then, is what may be termed the "history of the possible." All of the writers discussed in the chapters that follow speak, to some extent, from a U.S.-American location; it is the U.S. as a cultural, political, social, historical and juridical context which provides the framework for these authors' engagement of illness and disability. Yet, the point which they leave open, because they leave it unaddressed, is whether such engagement is possible only in the U.S.; there is clearly a danger here of American exceptionalism in the field of either disability studies or medical humanities. To what extent, then, do medical humanities accounts take their American location into account? Yet, the field of medical humanities as it has been institutionalized and anchored in medical training has by no means been confined to the U.S., and has flourished particularly in the Netherlands and in the UK. What may be needed for an American exceptionalism to be avoided, then, may be taking into account the location of medical humanities research and of life writing narratives. Yet, as has been argued, for instance, in the arenas of ethnic studies and diasporic studies, the U.S. may provide a framework for other, newly emerging fields to draw upon. If, in some contexts, the U.S. can draw on a longer-standing debate on disability studies, it would seem pointless not to use this debate as a potential blueprint or starting point for European discussions of disability. Yet, what may be considered on a different if somewhat related level is the role of the U.S. in the context of knowledge production and the dissemination of knowledge.

I am thus interested in the way in which "Americanness" is configured in different narratives: in the account of an Indian writer and poet with autism who has migrated from Chennai to Los Angeles; in a Bollywood film which chronicles the life of a Muslim man with Asperger's in the wake of the 9/11 attacks; in the performance of a Russian dancer who in the U.S. transformed his classical ballet into a particular kind of modern dance – complete with elements drawn from bioengineering technology – or in the life of a Canadian actor who became a naturalized American citizen and used his citizenship in a campaign to gain political support for stem cell research.

On a different level, this book is also concerned with the concept of autobiography, and the relationship of autobiography (or life writing more broadly conceived) to forms of disability and civic inclusion. A call for such inclusion, arguably, has been central to autobiography from the very beginning. Thus, slave narratives as autobiographies, beginning with Olaudah Equiano's *The Interesting Narrative of Olaudah Equiano or Gustavus Vassa, Written by Himself* (1789) testified not only to the authorship, but also to the humanity of the black subject.[4] It is this concept of autobiography, in turn, that I would like to restore to the framework of medical humanities. Even as medical humanities have centrally referred to the concept of lived experience as patient experience, emphasizing the role of the patient in and for medical treatment, the conceptualization of patient perspective may perhaps benefit from more careful framing. Moreover, a stressing of the concept of the autobiographical, as I will argue especially with regard to Jason Kingsley and Mitchell

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[4] See, for instance, Jeffrey Gunn, "Literacy and the Humanizing Project in Olaudah Equiano's *The Interesting Narrative* and Ottobah Cugoano's *Thoughts and Sentiments.*"

Levitz's account in *Count Us In* (1994), may also take into account those aspects of the life writing narrative that have nothing to do with illness in the first place.

In the chapters that follow, one narrative seems to require additional explanation: In a study otherwise concerned with life writing texts, I have chosen to include a narrative which is not literary, but filmic; and I have included a filmic narrative which is not autobiographical in the first place. Perhaps counterintuitively, then, I have included a Bollywood film titled *My Name Is Khan* to explore the ways in which autism may have come to be "mainstreamed" through popular culture, in a film which engages both "Indian" and "American" cultural imaginaries. While this feature film can easily be included in the framework of medical humanities, it cannot be seen as "life writing" in the sense proper. At the same time, many of the autobiographical narratives included here also explore the question of inclusion; there may hence be a continuity between *My Name is Khan* (2010) and for, instance, the Indian American autobiography *The Mind Tree* (2003) by Tito Mukhopadhyay. In investigating the role and potential relevance of medical humanities for American Studies, I am thus also interested in the difference, but also the continuity between life writing narratives and other genres which are similarly concerned with (the meaning of) "disability."

1.3 The Problem of Didacticism

One of the issues which are central in this context, then, may be that of didacticism. From the perspective of medical training, the use of life writing research and illness narratives clearly has a didactic purpose. These texts, it could be argued, need to be deprived of some of their aesthetic qualities in order to be read as patient narratives in the first place. What matters, then, is the question of perspective: These narratives about certain illnesses are read with regard to the patient's coping with his or her experience, and the patient's experience of a certain illness. It is hence the level of both experience and patient psychology which is important to medical humanities as it "imports" the humanities. The aesthetic qualities of a certain text, by the same token, must necessarily be disregarded as excess, as surplus; they cannot really be dealt with through the methodological toolbox of medical humanities. The question why a certain illness should be expressed in a particular genre –

the choice of poetry over a novel, for instance – seems to be of secondary importance for medical humanities. From a humanities perspective, on the other hand, this choice of genre would in itself be significant: The minute a given topic is treated in a particular genre – such as, for instance, the discussion of organ transplantation in a dystopia such as Ishiguro's *Never Let Me Go* (2005)[5] –, this will shape, even if it does not determine, the expression of patient experience and of narrative illness. Arguably, of course, *Never Let Me Go* is not an illness narrative; yet, it may nonetheless serve to draw attention to the power which genre may exert over the narrative that it contains.

Yet, crucially, the idea of didacticism may not only apply to the teaching of cultural, filmic, literary or poetic texts in a medical humanities framework, but also to the writing and reading of illness narratives themselves. It may also be pertinent, in other words, to the humanities as they come to deal with experiences of illness, partly in response to the emergence of medical humanities within the framework of medicine and of medical training. What is at stake here may in fact be the idea of the "activist" component in literary texts, and in the humanities practice of reading such texts. This question of didacticism has been addressed in recent literary criticism especially with regard to the emergence of ecocriticism as a discipline, and the related emergence of what Graham Huggan and Helen Tiffin have termed "postcolonial ecocriticism". In their recent study *Postcolonial Ecocriticism* (2010), Graham Huggan and Helen Tiffin explicitly address the question of genre, and its relationship to the didacticism of a given text. They use Indian writer and activist Arundhati Roy as a case in point. While Roy's debut novel *The God of Small Things* (1997) earned her the Booker Prize in 1997, she subsequently turned away from fiction toward activist non-fiction, and embraced ecocritical concerns. In tandem with this move away from fiction-writing towards more overtly didactic forms such as the essay, Roy's style and her tone became an overtly activist one: every sentence, its author implied, needed to be taken at face value. There was little difference, then, between the essay and the political pamphlet; in fact, Roy's activism seemed to take pride in this lack of difference. Writing for the (ecological) cause, she implied, had to be direct, and it had to be

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[5] I am indebted to Ruth Steinberg for this point.