Πονόμετρο δε βρίσκεται για να μετρά τον πόνο
τον πόνο τον κατέχουνε όσοι τον έχουν μόνο.

There is no instrument to measure pain
it can only be measured by those who experience it.
(Cretan *mantináda*)

Illness as Many Narratives

Arts, Medicine and Culture

Stella Bolaki

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Edinburgh University Press Ltd
The Tun – Holyrood Road, 12(2f) Jackson's Entry, Edinburgh EH8 8PJ

Typeset in 11/13 Adobe Sabon by
IDSUK (DataConnection) Ltd, and
printed and bound in Great Britain by
CPI Group (UK) Ltd, Croydon CR0 4YY

A CIP record for this book is available from the British Library

ISBN 978 1 4744 0242 2 (hardback)
ISBN 978 1 4744 0243 9 (webready PDF)
ISBN 978 1 4744 1151 6 (epub)

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Introduction

Illness as Many Narratives

This book starts from the premise that illness narratives are characterised by multiplicity. Among the texts and artworks I encountered in my research, few have driven this idea home (in all its different senses) to me more than my father's own cancer narrative. His untitled story is unfinished and remains unpublished, handwritten in a language that would not be accessible to an Anglophone audience without translation. Reading it a couple of years after his death in 2009, as two kinds of readers inhabiting the same body – a daughter and an academic equipped with various critical tools – I found myself being moved and intellectually intrigued by several of its features.

My father was trained as a mathematician, acquiring expertise in what I considered to be the ultimate discipline of abstraction, and never hid his admiration for numbers. Yet, with the exception of one mathematical equation he devises to explore the relationship between finite life and the concept of infinity (often treated as if it were a number in mathematics), the tools he uses to endow his experiences with meaning are narrative tools. This is not to say that his is a straightforward or single narrative. In its multiplicity of styles, it refuses easy categorisation: one can find diary sections with medical facts and details, but these are integrated into a larger life narrative, and the latter, in turn, into what has been described in literary studies as 'narrative of community'.[1] My father's story was, consciously or not, documenting not only the everyday rituals of illness and a body in crisis but also details of the rich local life of a Cretan village, where he grew up: the lives of its few remaining inhabitants (improvised stories that emerge, as his narrative indicates, as these people pass by the porch where he sat to write on their way to their daily business), small and large events, traditions under threat by a range of social and cultural changes in Greece; in short, a collective story with the ability to 're-enchant' his illness narrative by investing in other stories and encounters outside of the clinical framework of patients and doctors.[2] These narratives, personal and collective, are often interrupted by interpolated drawings (of his garden and the view of the sky's horizon from where he sat to write), signalling the need to turn to a visual medium to communicate aspects of his story better, as well as by what is known as *mantináda* (μαντινάδα in Greek), an oral tradition associated with poetry, music and performance.[3] Especially prominent on the island of Crete, *mantináda* refers to a compressed narrative or short poem that typically consists of rhyming couplets. It is often improvised and recited in the rhythm of accompanying music at feasts and other singing events. When composed and performed in this way, a verse elicits a response by another person and this in turn leads to another response – the dialogue continues until the end of the song. *Mantinádes* are much more than a means of entertainment. Many Cretans, especially the older generation, approach them as a fundamental way of expressing feelings such as love, pain, fear and loneliness and even as an *ars vivendi*, a Cretan 'art of living', which in the case of my father's illness experience was also a kind of alternative or complementary treatment.

In opening *Illness as Many Narratives* with my father's story, my aim is not simply to account for my personal interest in illness narratives (though scholarship in this area often still invites autobiographical justifications), but rather to raise a set of broader questions with which this book is also concerned: in (re)reading my father's story I knew that, as a representation, it did not offer unmediated access to his lived experience during the years of his illness. However, this does not lessen the work's expressive power; neither does the fragmentation, discontinuity or the switches to alternative genres, noted earlier, even as they draw attention to the contingent nature and inadequacy of verbal forms of communication, and the affective excess that cannot be contained by them. In gathering together the many different strands of his narrative performance, I wondered which of the stories or components in my father's account would be considered more relevant or 'fitting' for an illness narrative. Would a medical practitioner or educator skip the sections from his 'narrative of community' or try to establish connections across distinct narratives? What would critics of self-indulgent memoirs make of these vignettes that populate the narrative with the stories of the villagers, or of the *mantinádes*? How relevant is my father's national/cultural/professional background to the structure and the forms he chose for his narrative, and what kind of response do they call out in other people? What demands, if any, does his narrative make for anyone who encounters it, and how can these demands be met? What are the ethical and other potential questions raised by my particular mode of responding to this narrative here, or my responsibility in the future (for example, if I were to fulfil my father's wish to make his story available to others)?

Responding to the criticisms that narrative has received in the last decade or so after a period of enthusiastic reception within the growing field of the medical humanities,[4] *Illness as Many Narratives* offers ways to open up the category of illness narrative and the limited methods employed so as to produce more sophisticated and interdisciplinary readings of health, illness and medicine. It draws on important work that has been done in literary and cultural studies on the illness memoir but expands current understandings of illness narrative by adopting a comparative approach in its juxtaposition of arts/media and illnesses across and within chapters. I focus on a wide range of artistic and cultural representations – both autobiographical and collaborative projects, including mixed media forms – to create a more inclusive illness narrative canon that decentres the literary form as the paradigm for understandings of this genre and draws connections between different illness experiences. The works I discuss include photographic portraits, artists' books, performance art, theatre, film, animation and online narratives, many of which have yet to receive sustained attention, and treat breast cancer, liver disease, lung cancer, chronic fatigue syndrome and mental health. In enlarging the field's scope beyond canonical works and those bound by the context of biomedicine or merely the doctor-patient encounter, the following case studies challenge instrumental or reductive applications of the arts within the medical humanities, establish important links between medical and the broader culture and demonstrate how the arts/humanities and medicine can critically interact with each other. It is in all these ways that 'illness as many narratives' can be seen as furthering the work of the *critical* medical humanities.[5]

Illness narratives and the critical medical humanities

Illness narrative as a term is used across disciplines that inform the medical humanities, including medical sociology, anthropology and literary studies. Since Arthur Kleinman's distinction between illness and disease in the 1980s in *The Illness Narratives*, illness stories or narratives have been seen as giving expression to the subjective or lived experience of a particular disease or condition, which is distinct from the clinical definition of disease understood as an organic dysfunction within biomedicine (1988: 3–6). The subtitle of Kleinman's book, *Suffering, Healing and the Human Condition*, emphasises the need for patients to give voice to their suffering and for medicine to find ways to 'record this most thickly human dimension of patients' and families' stories of experiencing illness' (28). Typically illness narratives combine an auto/biographical narrative about living with an illness with reflections upon the wider implications of a particular disease, treatment, recovery and interactions with medical professionals. Kleinman's *The Illness Narratives* does not discuss published accounts of illness by patients and their families, but work by Anne Hunsaker Hawkins, Arthur Frank and Thomas Couser does. In *Reconstructing Illness* Hawkins examines the emergence of what she calls 'pathographies' in the late twentieth century through their relation to the religious conversion narratives that enjoyed a parallel popularity in earlier centuries, and considers the ways underlying myths and metaphors such as rebirth, battle and the journey give form to illness narratives. In addition to writing his own illness narrative (*At the Will of the Body*), Frank has offered a typology in *The Wounded Storyteller* by describing three narrative types: the 'restitution' narrative, the 'chaos' narrative and the 'quest' narrative. While Frank as a medical sociologist is primarily interested in situating clinical ethics and social science 'within a more general ethics of the body' and moving practitioners 'in the direction of thinking with stories' (1995: 23–4), literary critics like Couser (1997) have explored autopathography as a distinctive genre that has both enriched and challenged aspects of the repertoire of life writing.

Illness narrative has grown exponentially in the mid twentieth and twenty-first centuries.[6] Hawkins writes that 'it is surely no accident that the appearance of pathography coincides with the triumph of scientific technological medicine' (1999: xii). In *The Wounded Storyteller* Frank enlists the 'postmodern' (his study is published after Lyotard's 1984 account of the collapse of grand narratives) and the 'postcolonial' to capture rhetorically the 'writing back' to medicine that illness narratives effect (1995: 13).[7] A series of factors and changes after the 1950s seem to have contributed to an increasing interest in representations of illness, pain and suffering by people who experience illness first-hand or those who are close to them. Framing this study as it moves (though not following a strict chronological structure) from the politicised feminist patient of the late seventies through to the increasing use of social media to communicate illness experiences in the present moment, these factors include: medical professionalisation and specialisation affecting

doctor-patient relationships; the emergence of the women's, gay rights and disability movements, as well as the powerful influence of AIDS; and of course the popularity of certain life-writing genres (self-help narratives, memoirs) and technologies that facilitated self-publication. These advances remain relevant, and have expanded considerably in the age of the rapid development of digital technology and media convergence.

Illness narratives have garnered positive attention, and their contribution to narrative medicine has linked them with the notion of 'narrative competence' (Charon 2006: 12), turning them into tools that enhance clinical diagnosis and treatment and provide valuable insights to medical practitioners as well as patients. Despite this recognition, in 'The Limits of Narrative' medical humanities critic Angela Woods highlights a series of pressing questions about the use of narrative in an effort to reignite debate about its role in the field. The valorisation of narrative as 'the mode of human self-expression' (2011a: 74) promotes ideas of individual authenticity and a particular kind of self (neo/liberal, Western, middle class). These ideas have been equally questioned by social scientists who seek to locate illness narratives in a wider social context,[8] and by literary/cultural studies scholars who approach them as 'texts' or draw attention to a range of narratives (cross-cultural, queer) that challenge normative assumptions. Woods, however, more fundamentally highlights 'the normativity of narrativity' (76), in other words the suggestion that conceiving one's life as a narrative or story is fundamentally healthy, desirable and necessary. This is an assumption that characterises Frank's typology whereby the quest narrative is presented as an ideal to which everyone should aspire in order to reclaim and reorient the self that has been disrupted by illness:

> Restitution stories attempt to outdistance mortality by rendering illness transitory. Chaos stories are sucked into the undertow of illness and the disasters that attend it. Quest stories meet suffering head on; they accept illness and seek to *use* it. Illness is the occasion of a journey that becomes a quest. (1995: 115)[9]

Woods writes that 'narrative returns us again and again to structure, coherence and unity … What place is there for formlessness, for meaninglessness, for silence?' (2013: 125). Rather than arguing that we should 'discourage patients and doctors from telling stories or view with suspicion anyone whose sense of self is articulated in narrative terms', she suggests that scholars in the medical humanities can do more 'to foster a critical approach to the normative scripts of particular kinds of narrative', as well as 'more radically' move beyond narrative (2011a: 76).[10] The latter is framed as 'an invitation' that Woods believes 'scholars and practitioners in the medical humanities must be ready to accept' (2013: 126).

Woods' reminder of the limits of narrative is an important intervention in the field, but there is more to say about this term and the ongoing potential of illness narratives to shape wider debates about health, illness and the medical humanities. This is why the title of this book retains the term 'narrative' even as it defamiliarises it by linking it to different media and artistic forms. The proliferation of illness representations in contemporary culture attests to continuing forms of silencing at the hands of biomedicine while also informing a wide range of artistic and cultural practices. (Auto)pathographies and illness memoirs are well represented in illness narrative scholarship, but this is not the case for other media and artistic forms that intersect with narrative. Moreover, stories of particular conditions, and especially of mental distress, are comparatively fewer, and medical humanities is 'culturally limited by a pedagogical and scholarly emphasis on Western cultural artefacts' (Hooker and Noonan 2011: 79). This series of qualifiers, taken up in the following chapters, begs the question whether moving beyond narrative would be necessary or desired if we were to define narrativity more broadly[11] and multiply existing narratives. Even though some critics are adamant that this should be 'only a first step' (Sartwell 2000: 84), I would argue that there is room to challenge *and* expand narrative's conception and role within the medical humanities field, and that the works I consider in this book invite us precisely to do both.

There has been a tendency in the 'first wave of medical humanities', since its establishment as an identifiable field in the early 1970s (first in the US and later in the UK) and the rise of pathography in the 1980s and 1990s, to treat narrative as synonymous with verbal, if not literary, expression and to define it in terms of linearity and coherence. However, as scholars in literary studies and across disciplines have shown, illness stories often challenge chronological causality and unity. Cheryl Mattingly coins the term 'emergent narratives' to describe those stories (in her case within the clinical encounter) that, though still dependent on existing cultural resources, are 'embodied' and 'improvised' rather than told. Emergent narratives are 'clearly allied to performative views of narrative and action' and are not characterised by coherence but rather 'narrative drama'. Mattingly's description of 'how we follow a narrative suspensefully, always reminded of the fragility of events, for things might have turned out differently' (2000: 205) resonates with my discussion of film and performance in Chapters 4 and 5. Illness narratives take many forms and embrace different genres and media, some of which intersect with narrative as it is conventionally understood. In fact, two of Woods' proposed alternatives to narrative discussed in 'The Limits of Narrative' – metaphor and photography – function in this way, rather than as strictly anti-narrative modes. Woods herself acknowledges this when she describes metaphors as 'building blocks of narrative' that drive the story forward even as they lack the larger temporal structure of narrative (2011a: 76). Similarly, the myth of the photograph as a purely visual image has been challenged. Photographs often have captions and titles, if not a longer text attached to them; and as Victor Burgin and others have suggested, even when this is not the case, they are 'traversed by language' when they are interpreted by viewers (1982: 144).[12]

When approached as a communicative act and as essential to the process of meaning-making, narrative is not tied to a single medium. Alongside photography and forms that gesture towards narrative without appealing to elaborate stories (for example, the short animated film that has affinities with metaphor), this book focuses on works which, even though they do not rely exclusively on linguistic expression to give shape to experiences of physical and emotional distress, do not abandon it altogether. In this way, I show how the category of illness narrative can be opened up by addressing some of its limits and conservative assumptions from within, that is, through the works' own generic multiplicity and mixed-media nature that often lead to important aesthetic collisions. Thus word and image in photography; stories and images or distinct visual modalities in documentary film; text and the various other elements of an artist's book; performance art and theatrical conventions in autobiographical theatre; and animated drawing and documentary voice in animated documentary collide, but also enrich each other, in the following case studies. While acknowledging that the term illness narrative can be trivialised through overuse and overinflated, as Woods cautions, I believe that expanding rather than limiting current definitions and approaches to illness narrative can benefit medicine, the arts and cultural studies.[13] As the medical humanities is moving towards a new phase, taking stock of the need to forge alliances with the arts and humanities in order to remain pluralistic and experimental, it is a timely moment to recognise the many narratives of illness in all the senses of this phrase: the multiplicity of illnesses and their treatments; the different arts and media that need to be included in the field; and finally, the range of methods that will foster a more critical engagement with health, medicine and culture.

Many directions have been indicated in the last few years with the goal of enlarging the scope of the medical humanities and sharpening its critical edge. The medical humanities, we might say, suffers from an identity crisis, and nearly every conference or publication in the field includes a discussion of defining or redefining its name, boundaries and approaches. In its response to Howard Brody's three personalities of the medical humanities ('disciplinary list', 'programme of moral development' and 'supportive friend'),[14] the Centre for Medical Humanities at Durham University (2011) in the UK has recently suggested that 'those purposes are very much anchored within the culture and practices of medicine and are engaged in serving it'. The problem with conceptualising the field in an '"instrumental way" is that we prevent it from gaining sufficient distance from medicine to take a radically critical view'.[15] Woods, Anne Whitehead and Alan Bleakley, writing from different disciplines but intersecting in their interest in medical humanities, emphasise the need for a more critical medical humanities. Bleakley favours critique and resistance, a more interdisciplinary approach that avoids 'Western imperialistic tendencies' and a less 'utilitarian and artistically conservative model' (2014a: 23–4). Whitehead also takes issue with the dominant conceptualisation of the medical humanities in 'purely humanising or humanistic terms' (2014: 119). She proposes a shift from practitioner pedagogy and training (or an 'additive' view) towards a more 'integrated' view whereby the nature, goals and knowledge base of clinical medicine might be 'challenged and reshaped' rather than simply 'softened' by its encounter with the humanities (108). While in the following chapters I suggest that the value of the medical humanities is not limited to educational concerns, I am keen not to dismiss the distinct pedagogical potential of the artistic forms I consider – particularly the ways a more critical or radical pedagogy emerging from different sites and media can reshape and challenge existing practices within medical education.[16]

The discussion about the limits of narrative, like the debate about the goals and purposes of the medical humanities, has perhaps been divisive, but it does not have to be approached in purely negative terms. As a terrain where vital issues are being negotiated it has also served as a necessary precondition for renewed transformative articulations in the field, and thus as a form of giving new energy and impetus for conversation. This more positive view, which this book embraces, is evident in Keir Waddington and Martin Willis' journal special issue 'Rethinking Approaches to Illness Narratives'. They argue that 'the limited range of methods presently employed unnecessarily restricts what illness narratives might be allowed to mean, and even what they might look like' (2013: iv). Contributors to this special issue make a plea for 'reclaim[ing]the aesthetic and imaginative qualities from a system that reduces illness narratives (and healthcare more broadly) to nothing more than a further set of utterances that provide specialist medical data' (Willis et al. 2013: 68). Such utilitarian sensibility is something that often characterises approaches coming from the social sciences, where, typically, illness narratives are viewed as data to be solicited through interviews and then transcribed and analysed through certain methodologies. Even when this is not the case, the selection and analysis of illness narratives are normally framed by the doctor-patient encounter rather than other actors, and by the context of biomedicine, instead of situating their contribution in various aesthetic, historical and political traditions. Like these critics, Susan Merrill Squier argues in favour of the introduction of a more diverse set of literary texts and a new set of reading practices that 'can release us from the contract to which we are bound when we accept the implicit frame of both medicine and literature'. She envisages a more inclusive canon that would encompass not only canonical fiction and poetry, but also 'the full range of written cultural expression' (2007: 338). Whitehead similarly endorses the potential of the field 'to engage with an expanded notion of literary genre', including more experimental and 'mixed-media narrative modes' that redress the dominance of realist fiction and autobiography in existing scholarship (2014: 114).

In many ways such calls for more nuanced and sophisticated approaches to illness narratives are beginning to be addressed in the work of scholars trained in literary and cultural studies, including the aforementioned critics. Susanna Egan, for example, has explored the challenges disability and illness pose to autobiography and life writing more broadly, leading to generic experimentation, 'instability in perspective, narration, medium or authority' (1999: 28). Such approaches deconstruct the idea that illness narratives are linear or offer coherence, place narratives in historical and cultural contexts as opposed to following typologies, and intervene in more traditional approaches to literature such as Rita Charon's, which privileges a specific canon and approach to texts (realist fiction and autobiography, and close reading indebted to New Criticism). However, their contribution has not been recognised in mainstream medical humanities criticism, which still revolves around the influential models of Brody, Couser, Frank, Hawkins and Charon.

Neither, though, has scholarship on illness narratives been unequivocally embraced by literary and cultural studies. Many scholars working in these fields have had to actively make room for illness narratives to be considered worthy of literary or theoretical study. Both Lisa Diedrich and Ann Jurecic devote space to counter dismissive views of illness memoirs as 'victim art' and as 'nothing more than a self-indulgent mining of personal experience' (Diedrich 2007: xiv). Diedrich's study conceives illness memoirs as 'affective and effective histories' (xvii) and synthesises theoretical approaches which do justice to both the movements that can be found in such narratives: a movement *in* (the embodied self in relation to itself) and a movement *out* (the embodied self in relation to others; to institutions, including in particular the institution of medicine; and to communities, national and otherwise) (xix). Similarly, Jurecic confronts the suspicion towards emotion and testimony in the academy and argues against the view that *all* illness narratives distract from the structural through their unashamed valorisation of the personal. Responding to Rita Felski's call to consider the ordinary motives for reading and writing, Jurecic embraces illness memoirs for the challenges they present to literary criticism and models what she calls, after Eve Kosofsky Sedgwick, 'reparative' practices (2012: 105).[17] These practices can bridge the divide between mainstream medical humanities criticism, with its interest in the pedagogical or therapeutic/humanistic value of writing about illness, and literary criticism, which is perceived as valuing indeterminacy and complexity.

A central task for the critical medical humanities is to underline the limitations of narrow disciplinary approaches to illness narrative – that is, to show how rigid interpretations in both the arts/humanities and the social sciences fail to address the kind of *work* that these narratives do. *Works of Illness* by social psychologist Alan Radley opens with a series of debates concerning whether illness representations across different forms 'are good art' or constitute 'good science' (2009: 30). The common problem he identifies is that both camps approach such works as transparent windows into a person's experience. This in turn raises the thorny question of truthfulness, or opens the works to critiques of self-indulgence and of aestheticising illness. Focusing on the realm of arts and media with which *Illness as Many Narratives* is concerned, Radley looks at Arlene Croce's 1994 article in the *New Yorker,* 'Discussing the Undiscussable', which has become a common reference point for scholars working with illness narratives. As is well known, Croce refused to attend and dismissed the performance *Still/Here* by HIV-positive choreographer Bill T. Jones. In her words, she could not review someone who she 'feel[s] sorry for or hopeless about' (1994/5: 17). The performance elicited sympathy and 'a personal, emotional response' from the audience that made 'dispassionate analytical judgement' impossible (17).[18] Radley juxtaposes Croce's non-review with another controversy that also relates to people with AIDS: Jan Zita Grover and Douglas Crimp's commentaries against Nicholas Nixon's *Pictures of People*, a photography exhibition presented at the Museum of Modern Art in New York in 1988. While the exhibition gave faces to statistics by showing pictures of people with AIDS, it emphasised the personal and private rather than the public and contextual. The images, most of which were photographed close-up, exacerbated the victimisation of the subjects, thus eliciting pity as opposed to solidarity. As Radley concludes about the juxtaposition of the two debates:

> On the one hand, Croce strives to preserve art at the expense of hearing the voice of afflicted people. On the other hand, Crimp and Grover seek to empower afflicted people by freeing them from the representations of the photographer/artist, and of the media. At a superficial level there is a sense that art and illness do not mix, that the values of art ... cannot serve the needs of ill people. (2009: 23)

Radley clarifies that the scope of his study is not to determine whether representations of illness should be judged as 'art with a capital A', but to address 'why and how ill people might want to use artistic portrayal as the means to say important things about their experience and their situation. What can one say or show in this way that is not said more directly or more clearly from a medical, scientific or documentary perspective?' (38) Considering how people shape and give form to their experiences of illness for themselves and others shifts attention from the idea of the elevated self in autobiographical writing to 'the fabrication of illness in the modern age' (31). By examining the way works of illness '"do their job" both in the mode of presentation and in the apparent response that they call out in other people' (38), Radley shows how aesthetic practice, which is distinct from aestheticisation, can bear upon ethics as well as the spheres of medicine, science and the arts.

Despite their disciplinary and other differences, what emerges from this recent scholarship is that illness narratives do important work in the contemporary world but that doing justice to its complexity requires a set of tools that need to be actively fashioned. How to create 'critical practices that are grounded in everyday life, practices that are rigorous, compelling and, at the same time, socially engaged and thoughtfully empathic' is the question that motivates Jurecic's hybrid methodology (2012: 17). Diedrich notes of her own practice of 'crossing multiple domains – literary, philosophical, cultural, political, medical' – that it leads to a 'new object' that does not belong to the 'experts' of any of these individual domains (2007: viii). Radley, too, asserts that illness narratives are 'immune from being quite absorbed into the fields of art, medicine or science': 'Made in the interstices between these spheres they are fugitive and yet resilient to the extent that they retain their power to stand up, effectively to be *works*' (2009: 213). It is the active fashioning of tools, this constructive process that draws on different disciplines and perspectives, that I argue should be at the heart of the critical medical humanities.

What all of these urgent and ongoing debates demonstrate is that both in medical humanities scholarship and in literary/cultural studies there have been objections about narrative, and specifically about illness narrative; whereas moving *beyond* narrative is one invitation/provocation that individual disciplines perceive in distinct ways, whether they endorse it or not, another one, taken on in this book, is to continue fashioning tools and approaches that can attend to the polyvalent and important work that illness narratives do personally, culturally and politically. It is precisely this commitment that can generate and sustain the critical dimension of both illness narratives and the medical humanities. While the majority of the scholars mentioned above have shown the importance of expanding our responses to the illness memoir, this book considers a wide range of media and art forms whose aesthetic practices and cultural politics can be productively examined and re-contextualised under the umbrella of illness (as many) narratives and the critical medical humanities. This is not an exhaustive study, given that other illnesses as well as art forms and media, not to mention geographical and cultural contexts, could be addressed in relation to the chapters that follow. However, it is my hope that the critical approaches modelled can be translated across environments beyond what is covered here.

The case studies: towards a critical interloping

There is an assumption that the arts and illness should not 'mix', as already mentioned, but the sheer quantity of projects that treat illness, health and broadly-conceived medical topics demonstrate that they frequently do, whether this leads to controversy or not. Audrey Shafer notes that with the exception of art therapy and art practices within health and care settings, there are many artists, filmmakers and performers who may work with themes and issues of the medical humanities but do not affiliate themselves (or publicly associate) with the field. For Shafer, 'therein lies the next demarcation, dilemma and delight' for the medical humanities. As she explains, 'The delight is the welcome of front-line artists and interlopers from distant disciplines to the cause of medical humanities. The dilemmas include a snubbing of medical humanities as a dilute, noncritical mishmash of applied theory without academic depth, rigor or demarcation' (2009: 3). Shafer's choice of the word 'interloper' is a productive way of describing the work of recontextualisation and cross-fertilisation that takes place in the case studies of this book. The choice of art forms, genres and specific texts as well as juxtapositions/comparisons across and within the following six chapters participate in what I would like to call a *critical interloping* that works in two ways: inserting a variety of artistic and cultural representations that explore illness within the field of the medical humanities to expand its scope and existing approaches, and to create a more inclusive illness narrative canon; and at the same time modelling ways in which the arts and arts/media scholarship can enlarge their practices and critical approaches (for example on aesthetics, ethics, the body, disability and death) through more explicit dialogue with the critical medical humanities.

It could be claimed that the term 'interloping' has negative connotations, since it suggests an unwelcome presence or intrusion. Jo Spence, whose work is examined in Chapter 1, certainly felt like an interloper in the 1980s when she brought her photographic work to the medical community in the UK. As she writes:

> Within the [medical] orthodoxy, I occasionally met with pockets of resistance, glimmers of hope, as people talked about and practised more holistic attitudes towards health. Yet it still seemed difficult for them to understand that, as a photographer, I might have something to contribute to *their* debates. Medicine and photography fragment the same human bodies, if in different ways ... And if I was sick of medical people who viewed me as only an object of study of treatment, I was equally sick of academics within my own discourse who wrote theories of the representation of bodies, without in any way seeming to inhabit their own. (Spence 1995: 130)

Spence saw herself as an outsider from both the medical and academic communities, and her practice of phototherapy – contained neither within institutional frameworks of art therapy, nor documentary or artistic work on the body – can be envisaged in terms of bridge-building, or more polemically, as a form of critical interloping. I write *critical* because interloping does not simply entail adding a range of texts or genres but also, as the passage above shows, engaging with different methods and actively opening up space for them to reshape or challenge existing practices across disciplines.

While the value of the insights many artists bring to the medical humanities is more recognised today, it is difficult to shake dominant assumptions that the more 'relevant' representations, or those that 'belong' under the umbrella of illness narratives and the medical humanities, are those that are directly linked to medicine or focus explicitly on the doctor-patient encounter. This reductive or utilitarian approach prevents the inclusion of alternative genres, contexts and methods within the field, and in turn perpetuates the view of the medical humanities as a narrow area of study that has little to say to writers and artists not working within art therapy or in close collaboration with medical education programmes. Responding to this problematic view, *Illness as Many Narratives* argues for the need of more cross-fertilisation and mutually illuminating conversations between contemporary arts and media practices/scholarship and the fields of illness narratives and the medical humanities, as well as between medicine and broader culture.[19] The latter division is attached more to perceptions of Western 'scientific', rather than non-Western, medicine, and this is why the book's examples are drawn in their majority from a Western context. In showing how illness narratives resist being fully absorbed by either the concerns of the arts or those of medicine, and in the wake of the fascinating debate into 'the turn to memoir as a sign of either the exhaustion of theory or its renewed life' (Cvetkovich 2012: 3) in literary criticism, *Illness as Many Narratives* suggests that engaging with a range of illness narratives and multiple perspectives can help the arts, cultural studies and the medical humanities to overcome divisions and amplify the goals and scope of their respective work.

Though not referring to illness narratives per se, in their epistolary reflections on 'the productive tensions inherent in approaching medicine from multiple perspectives' (2004: 243), Squier and Hawkins testify to the importance of making connections across disciplinary methodologies. Citing Donna Haraway's call to forge 'an earth-wide network of connections, including the ability to translate knowledges among very different – and power-differentiated – communities', Squier and Hawkins conclude:

> Whether we teach in a university or a medical school, whether we write for humanities scholars or physicians, the medical humanities and cultural studies can enable us to make those connections: to see how bodies get made (and remade) in the hospital, the farm, the school and the home, and how in each site we have the choice to cultivate better, less compromised, lives. (2004: 253)

It is the task and challenge of forging, sustaining and expanding such dialogue and conversation, including critique, that should animate the medical humanities as it defines and redefines its future goals. The chapters that follow take on precisely this task by putting in practice the idea of critical interloping.

Illness as Many Narratives opens with two chapters that examine narratives about women's health, specifically breast cancer, and address both the politics of medicine and feminist responses to illness. This is a way of acknowledging the contribution of the women's health movement – which I should stress does not limit itself to breast cancer – to the critique of biomedicine and the development of alternative knowledges/practices about the body. By finding alignments between medical perspectives, feminist theory/activism, artistic practice, pedagogy and the lived experience of illness, the works I focus on in Chapters 1 and 2 open up medical understandings of the body and of breast cancer while also expanding limiting narratives about women's health within mainstream public discourse, such as that of the neoliberal postfeminist subject. Chapter 1 is the only chapter with a specifically historical emphasis, as it compares narratives of scarred bodies from the 1980s to the present. It stages a conversation between the work of two British photographers who have explored breast cancer, Jo Spence and Sam Taylor-Wood, and the responses to mastectomy and prosthesis/breast reconstruction of two American feminist critics/activists, Audre Lorde and Diane Price Herndl, who equally speak from different historical moments. In adding a new interpretative layer to Taylor-Wood's work, considered up to now primarily in the context of contemporary artistic practices and postmodernism, the chapter begins the kind of conversations between artists, theorists and medical humanities scholars that are necessary in order to introduce an alternative range of material and methods to forge a more critical medical humanities.

Despite their national and generic differences or the contexts in which they have been received, when read together, the photographs and texts I juxtapose in Chapter 1 share aesthetic concerns but also mark important stages in the representation of breast cancer and of the post-operative body during the twentieth and twenty-first centuries. As such these works, rather than simply having a private dimension, shape public perceptions and debates about: visibility and concealment in illness representations and the competing discourses of patienthood (politicised or not) associated with them, a topic addressed in the following chapters in relation to various media and illnesses rather than a historical shift; and the conditions under which photography can successfully usurp the power of the medical gaze to re-imagine or re-cover bodies – a subject that prepares the ground for Chapter 2, which focuses on doctor-patient encounters, as well as for subsequent chapters which examine other artistic practices as alternative forms of treatment.

Chapter 1 also introduces a central operation that underlies my notion of illness as many narratives, drawing attention to formal complexity, ambiguity and open-endedness as important tools for challenging instrumental approaches to the medical humanities and pointing to the more radical possibilities of the arts. The collision between narrative and image, or between certain kinds of conventions and the auto/biographical performance of illness – discussed here in relation to the tension between visible self/image and voice/caption, and in the context of feminist politics – is staged in subsequent chapters in relation to other illnesses, media and cultural backgrounds.

If in Chapter 1 Taylor-Wood and Herndl find new ways of inhabiting post-surgical bodies by balancing exposure and concealment or provocation and beauty in their narratives of re-covery, Chapter 2 turns to a form that equally negotiates the private and public and that historically has been associated with both aesthetic and political considerations, as well as with women's artistic practices. In examining the artists' books of Martha Hall, an American woman who unlike the women in Chapter 1 did not inhabit the 'identities' of artist, feminist or activist prior to her illness diagnosis in 1989, this chapter explores a medium that has rarely been discussed in relation to the medical humanities or breast cancer. The artists' books Hall created until her death in 2003 expand customary definitions of narrative, and document her interactions with the medical community as well as her development as an artist. Art historians and book critics typically describe the handling of artists' books in terms of a powerful aesthetic experience that emphasises the visual, tactile and other sensuous pleasures of the book. However, in synthesising approaches to fashion new tools that can mutually enrich the medical humanities and the field of artists' books, this chapter shows how Hall's books also engage and complicate ethical/political discourses of testimony and witnessing through their interactive form and content, thus placing a more radical set of demands upon their readers. As in the first chapter, I analyse the challenges Hall's work poses to mainstream breast cancer culture and the way in which her aesthetic strategies relate to politics. I also assess the provocations of her artists' books for medical communities, to whom Hall attached special importance, and suggest that her work creates spaces for unpredictable and unfinished relational encounters that can reinvigorate models of empathy in medical education. In this way I open up the question of pedagogy, specifically by reflecting on the importance of touch, which Chapter 3 examines further in relation to performance art.

Chapter 3 broadens the intimate context of ethical responsibility and embodied witnessing that artists' books stage for their various readers, as well as their pedagogical potential, by moving beyond the patient-doctor encounter. It shows how performance art can foster important forms of inter-relational and cross-cultural ethics/politics that expand understandings of medicine and treatment for both individual and social pathologies. The focus is on Mexican/Chicano performance artist Guillermo Gómez-Peña, whose work on immigration, politics of language and 'extreme culture', unlike Hall's, does not at first sight appear relevant to debates about illness and the medical humanities. In envisaging him as an interloper into these fields, I return to the key question of what we bring, or fail to bring, into medical education/humanities, raised in this Introduction. I argue that Gómez-Peña's work can enrich the medical humanities not only because it introduces a new 'provocative' medium or a set of 'extreme bodies' that draw on medical imagery, but also because it engages with a range of methods – most notably, radical pedagogical and political strategies – that can challenge instrumental applications of the arts/humanities. His body-based and spoken-word performances over the last thirty years, as well as the pedagogical methodologies that he has developed together with the art collective La Pocha Nostra, have established connections between disparate contexts and discourses. These include the early modern anatomy theatre and the freak show; the technologically augmented/post-human body; global geopolitical events; and, extending key tropes of the previous chapters beyond clinical conceptions of health, 'the *invisible* surgery' to which poor people, racial/ethnic minorities and disabled people are subjected in the popular media (especially since 9/11 and the War on Terror). In this chapter I show how this work speaks to current efforts to expand the province of medical ethics/humanities by addressing a wider context of pain, suffering and cultural healing, and how performance as radical pedagogy can dismantle authoritarian hierarchies and replace specialised knowledge with interdisciplinary dialogue, imagination and opportunities for increased individual and social agency. When La Pocha Nostra describe themselves not simply as artists but 'as radical pedagogues immersed in the great debates of our times', they voice a message that the medical humanities should adhere to so as to avoid shrinking into a narrow field and losing the breadth of vision that will keep it vibrant in the future.

The second part of the chapter turns to Gómez-Peña's solo performances, which explore his personal experience with illness and disability – specifically with liver disease and the risk of neurological damage after a viral infection. This work reframes and extends his earlier collaborative explorations of the body and border identity by creating palimpsestuous narratives that connect illness in the individual and in society and become vehicles for broader philosophical, political and artistic/professional struggles. As in the first two chapters, I examine the political ways of performing illness that Gómez-Peña adopts to counter neoliberal individualised ideas about health and risk management, setting the stage for a more extensive exploration in subsequent chapters of how knowledges and practices among different professionals – in this case, performance artists and medical educators – can be productively translated and used to forge closer critical conversations across disciplines. As I argue, Gómez-Peña's dilemmas about the place of his work in what he calls the era of 'the mainstream bizarre' and his commitment to more radical artistic and pedagogical methods, which do not preclude the possibility of failure, offer instructive provocations to the absolute faith in medicine as the solution to many problems, as well as to existing practices within medical education that recycle superficial forms of empathy and a less critical encounter with cultural difference.

The following three chapters shift attention to collaborative and relational narratives of illness, which are still not as well represented in the field, especially when turning to art forms and media beyond literature. The value of intersubjective and relational approaches to health and well-being has been emphasised recently as an important direction that the medical humanities should take in order to venture beyond a (still dominant in the field) 'neoliberal, humanist notion of

the individual body-subject' (Atkinson et al. 2015: 77), and the previous chapters have shown examples of illness narratives where we see this happening. Even though the work already considered does not foreclose collaboration, Chapters 4, 5 and 6 more explicitly address attempts to construct shared narratives, which are often fragile and demanding but also carry their own power. I continue the exploration of how we can challenge instrumentalising approaches to illness narratives by bringing in diverse materials and engaging with different methods, in this case collaborative; but I also raise a series of other questions, such as: what kinds of collaborations/relations do the narratives facilitate or efface? Do they document the many ways in which voices and perspectives can be joined together or instead break apart, and how does this process depend on the medium at one's disposal? In what ways do collaborative narratives complicate the distinction between self-authored illness stories and third-party ones, including how both are customarily received? Ultimately, what is the importance of collaborative methods in attempting to apprehend the experience of illness, and what can the medical humanities and the arts learn from instances of failing to do that?

Attention to third-person illness narratives has been primarily given to family and carer memoirs, and to doctors' narratives of their patients, which may involve a certain degree of co-constructed storytelling. These narratives have been examined as sites for mourning and remembering from psychoanalytic and political perspectives, as well as in the context of supporting individuals who for one reason or another (for example, due to serious communicative disorders) are unable to narrate their stories independently. Whether jointly authored or not, such narratives, while embraced within auto/biography studies for challenging the myth of the autonomous self,[20] often become sites of struggle; they are scrutinised in terms of the ways they negotiate power asymmetries and ethical quandaries relating to giving consent and the appropriation of another's story.[21] Questions of ethical responsibility surrounding artistic practice and spectatorship are important in Chapters 4 and 5, where they are examined in relation to documentary film and auto/biographical theatre. Following threads from previous chapters, these two chapters also reveal the ways illness challenges discourses of mastery, not only in the patient and the doctor but in other professionals too. I argue that a vision that engages with inadequacy and failure can be a productive means of rethinking a number of aspects which are of concern to medical education and the medical humanities, including professional competence, ethics and narrativity.

Chapter 4 discusses Wim Wenders' *Nick's Film/Lightning over Water* (1979–80). Filmed in the last few weeks before American director, and Wenders' friend, Nicholas Ray died of lung cancer, and edited twice, it has been, and continues to be, received with ambivalence by film scholars and viewers more widely, as well as by Wenders himself. The film's perceived failures are due to the difficulty of the subject it treats, which has attracted accusations of exploitation, and its formal self-consciousness, which documents its struggle to come together and successfully settle into one determinate category (for example, fictional film or documentary). While this early work, unlike other more immediately 'relevant' documentaries dealing with questions of death and bioethics, is not well known to medical communities either, I approach it as a collaborative project that becomes a form of 'terminal care' by supplementing medicine's power to largely define how to live one's final days, and presenting us with alternative treatments that can illuminate aspects of both filmmaking and medicine. Through the incorporation of several forms and media including staged documentary, fictional sequences, raw video footage, snippets from Ray's diary and voice-over commentary, the film enacts the process of trying and discarding different conventions and ways of representing illness and dying in film, and constructs distinct forms of witnessing for its collaborators and audiences. As in other case studies, this generic multiplicity allows Wenders to explore the tension between images and stories, loss and consolation, dying and its displacement, ethics and aesthetics, illness in the individual and in the cinema as an art form. These themes further show that illness narratives do not need to be framed by the context of biomedicine, but instead by a wider artistic and human context. Even though the film's ambiguity and the difficult ethical questions it raises are not resolved in the end, *Lightning over Water* affirms the need to continue creating new ways of looking at, and responding to, the experiences and relationships that it portrays. It is precisely the film's open-endedness and 'messiness' that can open a way beyond, on the one hand, the conviction that the values of art cannot serve the needs of ill people expressed by some critics, and on the other, narrow healthcare ethics approaches that equally close down critical conversations with other fields in favour of procedure and a set of moral codes.

Lisa Kron's play *Well* (2004), the focus of Chapter 5, is characterised by a similar 'messiness' and enacts the volatile process of telling a story when things do not go as planned. Not as familiar to medical communities as other plays that have gained popularity in medical education curricula, *Well* brings together autobiographical performance and more traditional theatrical conventions. It constructs a relational narrative of illness that draws on Kron's mother's experience with chronic allergies and on her own story of illness, treatment in an allergy hospital and recovery. While engaging with the uncertainties and debates surrounding contested illnesses such as chronic fatigue and multiple chemical sensitivity, the play intertwines the theme of illness in the individual with a discussion of illness in the community through its exploration of racial segregation/integration, thus opening up the medical to consider a wider context of health and well-being. With humour and ample metafictional gestures, the play gradually dismantles the initially chosen 'professional, theatrical context' in which to explore so-called universal questions of health, and challenges the previously erected oppositions between the healthy and the ill. Drawing attention to the fragility of joint/broken narratives in its content and form, *Well*, like *Lightning over Water*, foregrounds the challenges of the live event as well as of relating to another person. It shows how difficulty, inadequacy and the will to rework existing 'professional' practices can generate *other* ways of performing that can offer insight to the fields of medicine and medical education. Allowing her original agenda and expert knowledge to be affected (and infected) by the mother's and the other actors' interruptions, Kron learns the true meaning of integration – which applies not only to the community but, as I argue, to the play too: 'weaving into the whole even the parts that are uncomfortable or don't seem to fit'. Rather than an indication of failure, the doses of messiness that seep through the play's porous performance structure become signs of 'wellness'.

While Jo Spence met resistance in her efforts to demonstrate the relevance of her photography to public health debates in the 1980s, in recent years a whole range of unconventional media for representing illness are making important contributions and have the capacity to reach increasingly larger and more heterogeneous audiences, especially as they circulate via public broadcasters and the Internet. For example, the animated documentary has become part of the wider ways public health intersects with a vast web of media and forms, rather than consisting of images predominantly drawn from biomedicine. The potential for comics and animation to communicate embodied perception and subjective states of mind that are hard to describe has only begun to be researched in the medical/health humanities. The key focus of Chapter 6 is *Animated Minds* (2003), a series of short documentaries created in the UK to raise public awareness of different forms of mental distress including schizophrenia, agoraphobia, obsessive compulsive disorder and self-harm. These documentaries were created in a collaborative manner, and use real testimony for their soundtrack and various animation techniques by professional animators. Like artists' books and graphic narratives, animated documentaries communicate through an excess of elements – design, movement, shape, colour, texture, voice – despite the absence of conventional visually indexical material such as the body. By bringing together scholarship on the animated documentary as a genre and on witnessing in illness narratives, continuing to synthesise tools and critical approaches, I suggest that the animated documentary's evocative power, which allows it to penetrate subjective experiences, does not merely enlarge the epistemological parameters of live-action documentary. This would make its contribution too narrow, and relevant only to documentary studies specialists. Rather, the dialectic between 'absence and excess' and the distinct kind of self-reflexivity that characterise this form stage an ethical encounter for viewers that escapes either easy identification with the subjects of *Animated Minds*, or misidentification ending in stigma. In this way, and through the 'unfinished' nature of the *Animated Minds* testimonies, the films, like the other case studies, expand narratives about mental health and keep the practices of witnessing and response-ability open.

In addition to developing several of the ideas from previous chapters, such as the ethical responsibilities and challenges of collaboration, Chapter 6 returns to the politics of visibility with which *Illness as Many Narratives* opened. This is not in the (perhaps simplistic) sense that the mentally ill, rather than women with breast cancer, are the invisibly ill people of the twenty-first century, but by reflecting on the ways animated documentary negotiates a similar tension between concealment and visibility as the one addressed in Chapter 1. Animation problematises the idea of embodied presence through the replacement of the real person by an animated character, a kind of mask like the prosthesis that Lorde criticises through her illness performance of breast cancer, even as the soundtrack retains that connection in the documentary. Chapter 6 resituates this discussion of visible self and voice in the context of the complex relation of mental illness to both visibility and invisibility: in other words, in relation to the visual stereotyping of mentally ill people in the history of medical illustration and in mainstream media, as well as in relation to the difficulty of 'finding a language' for mental distress and the relative absence of a range of mental illness stories from public discourse. As the only chapter to explicitly discuss mental health issues, it also returns to common critiques of narrative/narrativity in the field of illness narratives, specifically the problematic assumption that certain forms of mental distress are inherently 'anti-narrative'. By looking closely at the *Animated Minds* audio testimonies, I underline the urgency of paying attention to such narratives and the experiences they document, many of which are surrounded with stigma, beyond an emphasis on pathology.

If the mixing of art and illness often causes heated debates, the mixing of illness and social media in the present moment creates its own controversies. The entrance of intimate embodied experiences, illness and dying into the digital sphere foregrounds questions of boundaries (how far to go with public self-representation online) and genre (are social media trivialising illness experiences?). Following on from the previous chapter, the Afterword offers a snapshot of the new media landscape of illness narratives that has developed in the so-called decade of Health 2.0, or 'participatory healthcare', drawing connections between the ethical, narratological and political questions for both authors and readers raised by these forms and those discussed in the previous chapters. Focusing on their distinctly public nature, immediacy and interactivity, I provide some final reflections on what online and collaborative platforms, and social media like Facebook and Twitter, add to our understandings of visibility, treatment and recovery, as well as to the intimate processes of witnessing and collaboration examined in the preceding chapters.

Throughout the case studies of this book, I argue for the importance of attending to the many narratives of illness, in all the different meanings of this phrase, and of engaging with a wide range of media and methods to forge more explicit and critical links between the arts, cultural studies and medicine so as to ensure that the medical humanities does not degenerate into a narrow discipline. A critical medical humanities can expand current understandings of illness narrative and enlarge the goals and scope of all these fields in ways that can enrich debates about health and illness in contemporary culture as well as cross-disciplinary enquiry more broadly.

Notes

1. See Zagarell 1998.
2. I allude here to the essay 'Imaginary Investments' (Willis et al. 2013: 67).
3. See the epigraph of this book for an example in translation. For a detailed discussion of the register and performative contexts of this tradition, see Sykäri 2009.

4. The term 'health humanities' has emerged as an alternative to the medical humanities to encompass practices that bear upon health outside of medical or scientific understandings, as well as to include a range of health practitioners who are not doctors, such as dentists, nurses, occupational therapists, social workers and others. See for example Jones, Wear and Friedman 2014 and Crawford et al. 2015. I see the critical medical humanities and the health humanities as having certain common goals, and my use of the former term throughout this book is not meant to reproduce the exclusivity that some critics have associated with the medical humanities. Also see Atkinson et al. 2015.
5. Ann Jurecic briefly uses the phrase 'illness as many narratives' in the concluding section of her study to resist narrow interpretations of illness stories, using as her example Anne Fadiman's ethnographic narrative *The Spirit Catches You and You Fall Down* (2012: 128). While the title of this book has been inspired by Jurecic's work, I have adopted the phrase to more widely explore illness narratives across several art forms and media, and to point to their multiple meanings, as outlined in this Introduction.
6. The historical dimension of illness writing prior to the twentieth century has not received the attention it deserves in medical humanities scholarship. See Waddington and Willis 2013 and Whitehead 2014.
7. On postmodern illness, see also Morris 1998.
8. See for example Atkinson 2009, and Woods' overview of these critiques in 'The Limits of Narrative'.
9. Frank further calls chaos stories 'anti-narrative', distinguished by an 'incessant present' tense that precludes temporal development (1995: 98–9). In the Afterword of the second edition of *The Wounded Storyteller* he complements this typology with three new types that acknowledge difficulty: 'life-as-normal narratives, borrowed stories and broken narratives' (2013: 193).
10. Woods engages with philosopher Galen Strawson's distinction between narrative and non-narrative (or episodic) people in 'Against Narrativity' (2004). Elsewhere (2013), she discusses the relevance of Crispin Sartwell and Sara Maitland's work to debates about narrativity and language. Though not examined in this book, such perspectives can offer insights into approaching stories by cognitively impaired people or those diagnosed with Alzheimer's (see for example Freeman 2008).
11. According to Shlomith Rimmon-Kenan, one of the things that illness narratives can teach narratologists is that narrative theory should be rethought 'in terms of contingency, randomness, and chaos rather than order and regularity' (2006: 243).
12. See also McKechnie 2014: 2 about the need to consider the role of the narratee, as opposed to simply the narrator, before assessing the limitations of illness narratives.

13. On multidisciplinary understandings of illness narrative, see Raoul et al. 2007, Mattingly and Garro 2000, and Hydén and Brockmeier 2011. On definitions of narrative across different media, see Herman 2007.
14. See Brody 2011.
15. The personality the Centre has proposed to emphasise resistance is that of 'disruptive teenager'.
16. On how pedagogy fits the 'pervasive calls' in the medical humanities literature for a more resistant model, see Shapiro 2012. On the two streams of the critical medical humanities, situated in medical education and medical humanities respectively, see Bleakley 2015.
17. See Felski 2008 and Sedgwick 2003.
18. For more discussion on this case, see Diedrich 2007, Radley 2009 and Jurecic 2012.
19. On medicine as culture, see Lupton 2012.
20. See Miller 2000, Eakin 1999 and Egan 1999.
21. See Egan 1999, Couser 2004, Tanner 2006, Diedrich 2007, Jurecic 2012, DeShazer 2013, and Frank's 'broken narratives' (2013: 201). In relation to co-constructed storytelling due to communicative disabilities, also see Hydén 2011.