

THE DEVELOPMENT OF NARRATIVE PRACTICES IN MEDICINE c.1960–c.2000

The transcript of a Witness Seminar held by the History of Modern Biomedicine Research Group, Queen Mary, University of London, on 18 June 2013

Edited by E M Jones and E M Tansey

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First published by Queen Mary, University of London, 2015

The History of Modern Biomedicine Research Group is funded by the Wellcome Trust, which is a registered charity, no. 210183.

ISBN 978 0 90223 898 5

All volumes are freely available online at www.histmodbiomed.org

Please cite as: Jones E M, Tansey E M. (eds) (2015) *The Development of Narrative Practices in Medicine c.1960–c.2000*. Wellcome Witnesses to Contemporary Medicine, vol. 52. London: Queen Mary, University of London.

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WHAT IS A WITNESS SEMINAR?

The Witness Seminar is a specialized form of oral history, where several individuals associated with a particular set of circumstances or events are invited to meet together to discuss, debate, and agree or disagree about their memories. The meeting is recorded, transcribed, and edited for publication.

This format was first devised and used by the Wellcome Trust's History of Twentieth Century Medicine Group in 1993 to address issues associated with the discovery of monoclonal antibodies. We developed this approach after holding a conventional seminar, given by a medical historian, on the discovery of interferon. Many members of the invited audience were scientists or others involved in that work, and the detailed and revealing discussion session afterwards alerted us to the importance of recording 'communal' eyewitness testimonies. We learned that the Institute for Contemporary British History held meetings to examine modern political, diplomatic, and economic history, which they called Witness Seminars, and this seemed a suitable title for us to use also.

The unexpected success of our first Witness Seminar, as assessed by the willingness of the participants to attend, speak frankly, agree and disagree, and also by many requests for its transcript, encouraged us to develop the Witness Seminar model into a full programme, and since then more than 50 meetings have been held and published on a wide array of biomedical topics.¹ These seminars have proved an ideal way to bring together clinicians, scientists, and others interested in contemporary medical history to share their memories. We are not seeking a consensus, but are providing the opportunity to hear an array of voices, many little known, of individuals who were 'there at the time' and thus able to question, ratify, or disagree with others' accounts – a form of open peer-review. The material records of the meeting also create archival sources for present and future use.

The History of Twentieth Century Medicine Group became a part of the Wellcome Trust's Centre for the History of Medicine at UCL in October 2000 and remained so until September 2010. It has been part of the School of History, Queen Mary, University of London, since October 2010, as the History of Modern Biomedicine Research Group, which the Wellcome Trust

¹ See pages 115–20 for a full list of Witness Seminars held, details of the published volumes, and other related publications.

funds principally under a Strategic Award entitled ‘The Makers of Modern Biomedicine’. The Witness Seminar format continues to be a major part of that programme, although now the subjects are largely focused on areas of strategic importance to the Wellcome Trust, including the neurosciences, clinical genetics, and medical technology.²

Once an appropriate topic has been agreed, usually after discussion with a specialist adviser, suitable participants are identified and invited. As the organization of the Seminar progresses and the participants’ list is compiled, a flexible outline plan for the meeting is devised, with assistance from the meeting’s designated chairman/moderator. Each participant is sent an attendance list and a copy of this programme before the meeting. Seminars last for about four hours; occasionally full-day meetings have been held. After each meeting the raw transcript is sent to every participant, each of whom is asked to check his or her own contribution and to provide brief biographical details for an appendix. The editors incorporate participants’ minor corrections and turn the transcript into readable text, with footnotes, appendices, a glossary, and a bibliography. Extensive research and liaison with the participants is conducted to produce the final script, which is then sent to every contributor for approval and to assign copyright to the Wellcome Trust. Copies of the original, and edited, transcripts and additional correspondence generated by the editorial process are all deposited with the records of each meeting in the Wellcome Library, London (archival reference GC/253) and are available for study.

For all our volumes, we hope that, even if the precise details of the more technical sections are not clear to the non-specialist, the sense and significance of the events will be understandable to all readers. Our aim is that the volumes inform those with a general interest in the history of modern medicine and medical science; provide historians with new insights, fresh material for study, and further themes for research; and emphasize to the participants that their own working lives are of proper and necessary concern to historians.

² See the History of Modern Biomedicine Research Group’s website at www.histmodbiomed.org.

ACKNOWLEDGEMENTS

The theme of this meeting came about as a result of several conversations between Brian Hurwitz and Tilli Tansey, both holders of Strategic Awards from the Wellcome Trust. Their discussions about a potential Witness Seminar on the beginnings and development of narrative practices in medicine were further stimulated by plans to hold an international symposium on narrative and healthcare at King's College (London) in collaboration with Columbia University (New York). The Witness Seminar, it was hoped, would bring 'added value' to each Strategic Award research programme.³ We are most grateful to Professor Hurwitz for his help in planning this meeting, identifying many of the key participants, and for so admirably chairing the meeting itself.

As with all our meetings, we depend a great deal on Wellcome Trust staff to ensure their smooth running: the Audiovisual Department, Catering, Reception, Security, and Wellcome Images. We are also grateful to Mr Akio Morishima for the design and production of this volume; the indexer Ms Liza Furnival; Mrs Sarah Beanland and Ms Fiona Plowman for proofreading; Mrs Debra Gee for transcribing the seminar; Ms Caroline Overy for assisting with running the seminar and Mr Adam Wilkinson who assisted in the organization and running of the meeting. Finally, we thank the Wellcome Trust for supporting both the Witness Seminar programme, and the KCL–Columbia collaboration that allowed several overseas contributors to participate in the meeting.

Tilli Tansey

Emma Jones

School of History, Queen Mary, University of London

³ For King's College Strategic Award, the 'Boundaries of Illness', see <http://www.kcl.ac.uk/artshums/depts/philosophy/research/projects/health/index.aspx> and, for the History of Modern Biomedicine Research Group's Strategic Award, Queen Mary, University of London, see 'Makers of Modern Biomedicine: Testimonies and Legacy', <http://www.histmodbiomed.org/> (both websites visited 3 November 2014).

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* Unless otherwise stated, all photographs were taken by Thomas Farnetti or David Sayer, Wellcome Trust, and reproduced courtesy of the Wellcome Library, London.

ANCILLARY GUIDES

Frequent mention of philosophers from antiquity to the present day are made in the following transcript; the resources below are recommended for detailed biographies and further information:

Craig E. (ed.) (1998) *Routledge Encyclopedia of Philosophy*. London: Routledge. An online, updated version of this resource is available, to subscribers, at: www.rep.routledge.com/ (visited 21 August 2014).

Zalta E N. (Principal Editor) *Stanford Encyclopedia of Philosophy*. Stanford University: <http://plato.stanford.edu/> (visited 21 August 2014): open access.

INTRODUCTION

Narrative medicine – or, to use a phrase Brian Hurwitz and I once coined in order to sell a book, narrative *based* medicine – has been part of the medical vocabulary for many years. Used by some as a proxy term for all the ‘soft’ things that are (or should be) taught at medical school – the humanities as applied to medicine; the study of meaning and meaning-making by patients and health professionals; professionalism and medical ethics; and what Martha Nussbaum has depicted as the liberal arts education that hones the reflexive judgements essential for participating in a true democracy¹ – ‘narrative medicine’ is at once a legitimate component of the medical curriculum and fundamentally incommensurable with its rationalist assumptions and logic.

In 1938, sociologist Robert Merton set out the defining characteristics of scientific inquiry: communalism, universality, disinterestedness, objectivity, and organized scepticism.² Medical *science* adheres closely to these principles, privileging the objective pursuit of universal (or near-universal) truths about the causes, treatment, and prevention of disease through experiment and observation. Medicine as *narrative* has diametrically opposite characteristics: it is individual, subjective, perspectival, and relentlessly contextual. The narrator speaks to, writes for, or acts to an audience – who are expected to be interested, not disinterested, in what is being narrated!

Yet whilst clinical medicine draws on science, it is not itself a science. Rather, it is an *ethical practice* (what best to do for the patient in a particular set of circumstances?)³ – and therein lies the opportunity (nay, the requirement) for a narrative component. Indeed, as this seminar illustrates, one early and significant achievement of narrative medicine was to rescue clinicians and patients from an almost exclusive reliance on a rules-based (‘principlist’) approach to medical ethics and expose them to the more overtly case-based (virtue) ethics of Aristotle and those who built on his work.⁴ The historical struggle between the principlists and ‘anti-principlists’ in the teaching of ethics in medical schools, and its application in medical schools, is discussed at some length (pp. 48–53).

¹ Nussbaum (2012).

² Merton (1938).

³ Montgomery (2005).

⁴ MacIntyre (1984).

The tension between narrative medicine as, on the one hand central to, and on the other hand antithetical to, the medical curriculum is quick to surface in the discussion reproduced here between some of the great scholars in this field. Kathryn Montgomery, for example, looks back on her early days of teaching literature in a medical school and recalls that she and her colleagues, who had been hired to provide a counterpoint to the fast-paced, facts-based, and narrowly biomedical modules offered by medical professors, ‘could keep them [medical students] interested in patients as they went through the great grinder’ (p. 11).

The speakers in this seminar – whose disciplinary backgrounds include English literature, linguistics, philosophy, bioethics, medicine, pharmacology, neuroscience, general practice, sociology, and medical education – describe how the introduction of narrative medicine played out in medical schools across North America and Europe within their professional lifetimes. In some cases, there was an ‘inspired’ dean who viewed narrative medicine, in all its variants, as the primary and fundamental basis of the education of doctors. In others, narrative medicine was included as the optional side salad to the meat and potatoes of mainstream medicine. In such cases, it was sometimes little more than a tick on the dean’s checklist and brought the distinct possibility of a ‘bad’ narrative medicine, naively delivered by a faculty who knew no other definition of quality than Merton’s principles of science and the bare bones of principlist ethics.

From the speakers’ accounts, it would appear that in the second half of the twentieth century, even when narrative medicine was endorsed by the top brass at a medical school – and especially when it wasn’t – getting and keeping the narrative perspective on the agenda was an uphill struggle that required considerable skills in realpolitik. And, as Arthur Frank points out, not only was the patient as a person absent from the medical textbooks of the 1960s and 1970s, he or she was also absent from sociological textbooks of the same period, since that discipline’s core curriculum at the time offered the sociology of medicine, the sociology of professionalism, but no sociology of actually *being ill* (p. 15).

The mid-twentieth century spawned the expert system and valorized abstraction to an extraordinary degree, allowing Merton’s principles of objectivity and disinterestedness to legitimize research studies such as ‘The Longitudinal Study of Untreated Syphilis in the Male Negro’ at a time when effective treatments for this life-threatening condition were available and affordable.⁵ As Frank notes in passing, the Tuskegee study was deeply shocking only in retrospect. At the time, science, having carefully abstracted its collaborative and universalist pursuit

⁵ Rockwell, Yobs and Moore (1964).

of the truth from the individual personal suffering of ‘research subjects’, was answerable only to itself (p. 47).

The ‘witnesses’ in this seminar depict their efforts to introduce the narrative study of the patient’s experience as consistently rewarded – often handsomely – by the profound effect of such teaching on the students and residents who participated in it. At this point, my inner quantitative researcher whispers ‘biased sample?’, prompting me to ponder whether a collection of individuals selected for their international reputation as both narrative scholars and medical educators could produce anything other than positive impacts on intelligent and ethically motivated students who had, up to that point, been starved of exposure to the arts and humanities.

A less distinguished group of speakers might (in the absence of a tape recorder) have shared accounts of courses in narrative medicine that students had experienced as dull, pointless, frustrating, and even downright wrong. With a passing acknowledgement to this possibility, I encourage the reader to enjoy the accounts of ‘what good looks like’ – or, more accurately perhaps, what, in retrospect, good is remembered as. And in the collective memory of most of these participants, it was, by and large, the professors of medicine who variously misunderstood, devalued, or failed to notice narrative medicine and the students who embraced it and allowed themselves to be transformed by it.

Brian Hurwitz, who shifts between participant in the dialogue and Chair of the meeting, seeks to steer the discussion to a satisfying denouement. Wearing his Chair hat, he asks: ‘Are we moving towards some kind of assimilation of narrative thinking and teaching into mainstream healthcare?’ (p. 53). No, say many of the seminar’s participants. If anything, it’s getting worse. For Jane Macnaughton, the problem is the inexorable formalization of the humanities curriculum into bite-sized ‘student selected components’ (SSCs) modelled on the same standardized, skills-based format of all the other SSCs (pp. 53–54). Gone are the opportunities to join a Lit. Crit. class and have one’s progress assessed by the same criteria as the indigenous humanities students.

For Jens Brockmeier, the key block to mainstreaming narrative medicine is the evolution of narrative studies from a ‘structuralist’ framing (‘a well-defined story, a clear-cut definition of what narrative is and what it is not, a basic vocabulary...’, p. 55) to what he calls a ‘post-classical’ era in which the links between narrative and literature, and between narrative and text, and the distinction between fiction and non-fiction, are all called into question. Citing

Wittgenstein, Brockmeier redefines narrative as a ‘form of life’ rather than a discourse (p. 56) – heady stuff for the medical school dean who has only just learnt that ‘narrative’ means (more or less) the same as ‘story’.

For Arthur Frank, the block is the ‘neoliberalization’ of medicine – that is, its reorientation to the logic of the market, with its core values of choice and competition and its relentless drive to monetize all aspects of human existence and experience (p. 59). Inevitably, the caring relationship and Rita Charon’s important concept of ‘narrative competence’ are downgraded and removed from the equation. Medical schools, says Andrew Elder, are ‘bigger and busier’ than they used to be (p. 68). In extreme cases, says Jane Macnaughton, this trend results in the ‘crisis of compassion’ that was evident in the Mid-Staffs scandal (p. 61).⁶ Students and young doctors embody in their practice the tension between market and humanistic values, and, suggests John Launer, this is one of the main reasons why they sign up for his Master’s-level programmes in narrative medicine at the Tavistock Clinic.

Craig Irvine disagrees that narrative medicine is becoming less mainstreamed. As a teacher at Columbia University, he believes it is ‘decades of working together’ that has brought the two cultures of scientific and narrative medicine to a position of mutual understanding and respect (p. 57). Rita Charon, from the same medical school, agrees that there is much to celebrate at Columbia, and attributes this primarily to the strong institutional culture and the fact that narrative medicine is an integral and compulsory part of the curriculum not only for students of medicine but also (imminently) for nursing and dentistry students too.

John Launer and Jeff Aronson argue the position of narrative medicine vis-à-vis evidence based medicine (are they in opposition, or complementary, to one another?) (pp. 58–9). I am tempted to point them towards an attempt at a new synthesis of these paradigms (‘the Campaign for Real EBM’) by a group I led, called the Evidence Based Medicine Renaissance Group – though the link with ‘Renaissance Man’ was probably lost on most *British Medical Journal* readers. I quote from that paper:

Real evidence based medicine has the care of individual patients as its top priority, asking, ‘what is the best course of action for this patient, in these circumstances, at this point in their illness or condition?’. It consciously and reflexively refuses to let process (doing tests, prescribing medicines) dominate outcomes (the agreed goal of management in an individual case).

⁶ See note 192.

It engages with an ethical and existential agenda (how should we live? when should we accept death?) and with that goal in mind, carefully distinguishes between whether to investigate, treat, or screen and how to do so. [...]

Importantly, real shared decision-making is not the same as taking the patient through a series of if-then decision options. Rather, it involves finding out what matters to the patient—what is at stake for them—and making judicious use of professional knowledge and status (to what extent, and in what ways, does this person want to be ‘empowered?’) and introducing research evidence in a way that informs a dialogue about what best to do, how, and why. This is a simple concept but by no means easy to deliver. Tools that contain quantitative estimates of risk and benefit are needed, but they must be designed to support conversations, not climb probability trees.⁷

These paragraphs were penned with the explicit aim of creating space for negotiation between the ideas and perspectives of narrative medicine, discussed so engagingly in this Witness Seminar, and the evidence based medicine movement. The latter has dominated medical schools (and medical research) for the past 20 years and imposed a value system based on positivistic assumptions, linear decision models, and a rigid, epidemiology-derived ‘hierarchy of evidence’. I am cautiously confident that evidence based medicine, at least at its more enlightened margins, is now ready to shed these intellectual shackles and accept a more pluralist epistemology. If I am right, the future for narrative medicine may be brighter than many of the speakers at this seminar feared.

Professor Trisha Greenhalgh

Queen Mary, University of London



Figure A

⁷ Greenhalgh, Howick and Maskrey (2014).

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Participants*

Professor Jeff Aronson

Dr Catherine Belling

Professor Jens Brockmeier

Professor Rita Charon

Dr Andrew Elder

Professor Arthur Frank

Professor Anne Hudson Jones

Professor Brian Hurwitz (Chair)

Dr Craig Irvine

Dr John Launer

Professor Jane Macnaughton

Professor Kathryn Montgomery

Professor Maura Spiegel

Professor Tilli Tansey

Attending the meeting: Dr Nils Fietje, Dr Neil Vickers

Apologies include: Professor Eric Cassell, Professor Larry Churchill,
Professor Trisha Greenhalgh, Dr Jeremy Holmes,
Professor Lars-Christer Hydén, Professor Dori Laub,
Professor Vieda Skultans, Professor Gareth Williams.

* Biographical notes on the participants are located at the end of the volume

Professor Tilli Tansey: I'm Tilli Tansey and I'm the Head of the History of Modern Biomedicine Research Group now based at Queen Mary, University of London and funded completely by the Wellcome Trust. The purpose of these Witness Seminars is to record your experiences. We want to hear your stories: What was it like? What happened? How did narrative medicine as a specialty in your lifetime get started? It is a very new specialty; it's also perhaps the oldest specialty. Narrative medicine as the subject of this meeting has happened very largely because of Brian Hurwitz's interest and his skills: listening to patients, recording, understanding what patients are saying and what fellow professionals are saying, and his expertise. Brian and I are both holders of Strategic Awards from the Wellcome Trust, and a collaborative meeting on this topic seemed very timely.¹ This is a very different kind of meeting from the ones we normally have which are directed towards modern biomedicine. Brian needs little introduction



Figure 1: Professor Tilli Tansey

¹ A conference entitled 'A Narrative Future for Healthcare' took place at King's College, London 19–21 June 2013 in partnership between King's College Centre for the Humanities and Health, London, and the Program in Narrative Medicine of Columbia University, New York, and involved several participants in this Witness Seminar. See <http://www.kcl.ac.uk/innovation/groups/chh/Narrative-Medicine-Conference-/About-the-Narrative-Medicine-conference.aspx> (visited 15 May 2014). See also Hurwitz and Charon (2013).



Figure 2: Professor Brian Hurwitz

to this audience; he's Professor of Medicine and the Arts at King's College, London. He is a practising general practitioner, but he has a keen interest and very distinguished reputation in narrative medicine, in medical humanities. So without further ado, I'm going to hand over to Brian for the rest of the meeting.

Professor Brian Hurwitz: Thank you all for coming. I know some people have come a long way, others not very far but it's very good to see you. I have formulated the high level aim of this seminar as exploring the intellectual origins, and the institutional and interpersonal groundings of what, at this stage, I refer to as self-consciously developed narrative practices relating to healthcare in the latter half of the twentieth century. That's quite a general aim and if we focus on it in terms of an objective, it's to recall and to reconstruct how narrative assumptions, methods, writing practices, and claims to knowledge and technique came to engage with the world of health and healthcare in the latter half of the twentieth century. We're a broad, multidisciplinary assembly here and I'm keen for everyone to contribute as much as they wish to. Please don't feel that you have to make a short contribution; I want to bring out whatever it is that you have to say in its fullness. The session is structured by chronology in two main periods: what happened in the second half of the last century and what has taken place since then.

<p>Pre-2000</p> <p>Narrative theories and practices pre-1970s</p> <p>How did narrative thinking in relation to health arise and gain footings between c.1970–2000?</p>
<p>2000 and beyond</p> <p>Growth and development of narrative theories and practices in healthcare – networks of writing, research, and education</p> <p>Is a synthesis of different approaches to understanding and developing the power of narrative knowledge and perspective in relation to health possible?</p>

Table 1: Witness Seminar outline programme.²

I want to start by thinking about theories of narrative and narrative practices pre- the 1970s, and to do that by asking Kathryn Montgomery: when you arrived at Northwestern University, Kathryn, in the 1980s, how aware were you of developments in narrative thinking at that time?³ Of a growing literary theory of narrative, say, or the work of Walter Benjamin on storytelling in the 1930s,⁴ or the approaches of more social science-oriented researchers such as Labov in the 1960s?⁵

Professor Kathryn Montgomery: I began well before that in the medical school at Morehouse College, Atlanta, in the 1970s, and then for most of the 1980s I was at the University of Rochester, so do you want me to start with that or shall I begin with Northwestern?

Hurwitz: I want you to start as early as you can remember.

Montgomery: Well, I think in the United States the people who were first engaged – three of us are sitting here⁶ – in literature in medicine, teaching

² A draft outline programme was circulated to seminar participants to comment on in advance of this meeting. Table 1 is the final version of that programme, used as a framework for this seminar.

³ See Appendix 1 for an ‘Outline of narrative medicine’s development at institutions and by individuals in the USA and UK’, pages 75–6.

⁴ Benjamin (1970). See, in particular, chapter entitled ‘The Storyteller: Reflections on the work of Nikolai Leskov’, pages 83–109.

⁵ William Labov (b. 1927) is Professor of Linguistics, University of Pennsylvania; <http://www.ling.upenn.edu/~wlabov/> (visited 28 February 2014). See, for example, Labov and Waletzky (1967).

⁶ Professors Rita Charon, Anne Hudson Jones and Kathryn Montgomery.



Figure 3: Professor Kathryn Montgomery

literature in medical schools were unusual in one way or another. Let's see, there were at least two people who were eighteenth-century English literature scholars, there were some Virginia Woolf scholars, three perhaps, at least three, and this is in the early days, and at least one person in comparative literature. As a group we were, I'd say, dissenters from formalism; that is we'd been trained in New Criticism but for the most part – given the fields we were interested in – you can't live a New Critical life in eighteenth-century studies, you've got to look up some footnotes, you've got to know what things mean.⁷ And comparative literature is the same. Virginia Woolf cries out for the biographical fallacy. So I think all of us were very well trained in formalistic approaches, and various ones of us knew one thing and others of us knew another. One surely knew about Vladimir Propp and the Russians.⁸ By and large, though, we were not taken with French deconstruction as the 1980s and 1990s went on – we knew about it but it didn't really apply to teaching in a medical school.

⁷ New Criticism is a literary movement that originated post-World War I. Its advocates call for the close reading of works of literature. See, for example, Ransom (1941).

⁸ See, for example, Propp (1958).

Politically, our best arguments for keeping our jobs were practical, so we used Enlightenment arguments that would make, you know, Foucault shudder.⁹ In fact, I have a colleague, Tod Chambers,¹⁰ who would have some things to contribute to this forum, who, when we used to interview graduate students on the Evanston campus (Illinois) for short five-week seminars in the medical school that they could invent on their own and teach on their own and get paid as well. We would interview one after another and he would say, ‘Drank too much Foucault.’ But does that answer the question?

Hurwitz: Well, you’re speaking as if there is a sort of group identity at this time and is that correct?

Montgomery: Yes. In the US.

Hurwitz: And that is composed of literary scholars who decide presumably for some reason or another to go and work in medical schools. Is that right?

Montgomery: And then there are these outliers like Art Frank, right here, who comes in out of the cold from Canada and sociology and he knows theory and he begins to apply it.

Hurwitz: Could I just ask what is it that takes you into the medical school environment at that point? Are you conscious at the time of the development in the late 1960s at the University of Pennsylvania, at Hershey, that there is a humanities department?¹¹ Is that an important influence or not?

Montgomery: Yes. It is an important influence, most definitely. I had a grant from something called the Institute on Human Values in Medicine that Edmund Pellegrino was a president of, who passed away just two days ago.¹² I

⁹ Michel Foucault (1926–1984), the French historian and philosopher. See, for example, Foucault (1986).

¹⁰ Tod Chambers is Associate Professor of Medical Humanities and Bioethics, Northwestern University Feinberg School of Medicine, Chicago, USA; <http://fsmweb.northwestern.edu/faculty/FacultyProfile.cfm?xid=14542> (visited 3 March 2014).

¹¹ For a history of the Department of Medical Humanities, see Kirkner R M. (2012); an article published on the blog of the Penn State Milton S. Hershey Medical Center and Penn State College of Medicine.

¹² Edmund Pellegrino (1920–2013) was President of the Institute on Human Values in Medicine from 1971 to 1981, and was Professor Emeritus of Medicine and Medical Ethics at the Kennedy Institute of Ethics, Georgetown University, Washington DC, USA; <http://www.georgetown.edu/news/pioneering-bioethicist-edmund-pellegrino-dies.html> (visited 3 March 2014). For further biographical details see Wildes (1990). See also, for example, McElhinney and Pellegrino (2001).

got a grant to go around and look at the six schools that had any humanities in the medical school at all. And, of course, Pennsylvania was a major place and so was Galveston, University of Texas.

Hurwitz: Could you say a little bit about what took you into medical school at this time?

Montgomery: Personally, you mean? I taught at Morehouse beginning in 1964. As some of you may not know, it is quite a prominent African American liberal arts college for men in Atlanta. At the time it was quite elite. It began to resemble state colleges after the prestigious north-eastern schools began admitting African Americans as the 1960s went on. I like to think of the *The Cosby Show* as kind of a model for where families sent their children.¹³ The first really bright child who applied herself to the books went to a north-eastern school and the next equally smart, but not bookish, kid went to Spelman, the women's college across the street from Morehouse. Lisa Bonet's character went to Spelman – you may recall if you watched the television show.¹⁴ We had quite bright people and continued to because there were a lot of 16-year-olds who had double 800s – 'perfect' scores – on their college boards whose mamas wouldn't let them leave town. Freshman English was required and so was a sophomore literature survey. Freshman English was a composition course because, as we used to say, 'God forbid a Morehouse man goes out into the world with Martin Luther King's reputation preceding him and not be a good public speaker and a good essay writer, and so forth.' So the wiser heads did not excuse young men with advanced placement credit from freshman English, they excused them from the sophomore survey of English and American literature, which makes sense.¹⁵ That left a bunch of 16- and 17- and 18-year-old students mighty fussy because they 'shouldn't have to take freshman English'. So we had honours courses and I invented one called 'The Evolution of the Idea of Evolution'. And, in short

¹³ *The Cosby Show* was a popular television situation comedy broadcast during the 1980s in the USA; see http://www.carseywerner.com/shows_about.php?showid=2 (visited 3 March 2014).

¹⁴ Lisa Bonet played Denise Huxtable in *The Cosby Show*.

¹⁵ 'The Advanced Placement Program (AP) enables willing and academically prepared students around the world to pursue university-level studies while still in high school, with the opportunity to earn credit (points toward an undergraduate degree) or advanced placement (the opportunity to skip an introductory level university course). AP is recognized in the admissions process by more than 4,000 universities worldwide, and outside the US, more than 600 universities in more than 60 countries recognize qualifying AP Exam scores.' Quoted from College Board International's website; <http://international.collegeboard.org/programs/advanced-placement> (visited 14 August 2014).

order, I was teaching all the pre-meds. I got curious about why they came back at homecoming so depressed and then, when we began planning the medical school at Morehouse, I got roped in and found it really quite interesting.

Hurwitz: So that was a new medical school just starting?

Montgomery: And it grew out of, I was a perfectly ordinary literature professor minding my own business who got taken away.

Professor Anne Hudson Jones: I was just going to add, when Kathryn was talking about receiving that award from the Institute on Human Values in Medicine and visiting the medical schools at that time that had humanities programmes: I think the only one perhaps in addition to what you were doing at that time, Kathryn, was Penn State, Hershey, with Joanne Trautmann, and I think we really should mention her name here because she was the first full-time Professor of Literature appointed to the faculty of a medical school in the United States.¹⁶ I think she had an influence on all of us who then began doing that work in the years afterwards.

Hurwitz: There were other professors of other humanities disciplines at the Hershey medical school, weren't there? There was a professor of philosophy, history, religious studies.

Hudson Jones: So when Kathryn visited Galveston, for example, I was not there yet.

Montgomery: I wasn't going to say that. I always thought, perhaps, I could persuade Galveston to create a position and they did, and they hired Anne.

Hudson Jones: So that was just the little footnote I was going to put there.

Hurwitz: Could I ask, following up on that point, what was it like working as a humanities scholar, researcher, teacher in a medical school at that time? What were your role models? What were the intellectual influences you felt to be important then?

Montgomery: Dan Clouser at Penn State, the philosopher there, once said – remember this is the early or mid-1970s – ‘You don't do philosophy till they have you up against the wall.’¹⁷ That was a strong influence on me, as Jo was when I visited, Joanne Trautmann, later Joanne Trautmann Banks, at Penn

¹⁶ See biography on page 87. For an obituary see Oransky (2007).

¹⁷ Danner Clouser (1930–2000) was University Professor of Humanities at Penn State College of Medicine, USA, (1968–1996). For an obituary see Anon (2000).



Figure 4: Professor Anne Hudson Jones

State. She maintained, quite rightly, that you could read *Oedipus Rex* and elicit everything you needed to know from the students without asking them what Aristotle says about tragedy.¹⁸ You could supply that because they are medical students, they are not duty-bound to know Aristotle's *Poetics*. And that was an influence on me as well.

Hurwitz: What was understood at that time by the decision of some medical schools and some far-sighted deans to establish departments of humanities in medical schools? I'm aware of various attempts to explain this phenomenon but what did you think these medical schools were trying to do and how were you, yourself, enabling of that purpose?

Montgomery: At Morehouse, Edmund Pellegrino came to visit and said, 'You should just turn medical education around.'¹⁹ Have students study the sciences as undergraduates and do humanities and all the clinically oriented things which would be humanly oriented in medical school.' But the big selling point at Morehouse was that we could help keep the school focused on primary care medicine, which was very difficult at the time, keep them interested in patients

¹⁸ *Oedipus Rex*, a Greek tragedy by Sophocles (496–406 BC) was frequently cited by Aristotle (384–322 BC) in *Poetics*. Aristotle (1968).

¹⁹ See note 12.

as they went through the great grinder. And in all of this I think you would have to take into account the organization of US medical education then, Canadian too, except for McMaster University. These are graduate students, these are 22-year-olds. They went to school 32 hours a week, went home, and supposedly read 100 or 125 pages a night and took frequent exams because professors would get jealous of one another, because students were cutting classes to study for another professor's exam. It was just maddening. The Association of American Medical Colleges' report on the 'general professional education on the physician', which called for a reduction in class time and implicitly a reduction or contraction in science education, was a real boon and curriculum reform has gone on from there.²⁰ So at my second medical school, the University of Rochester, I was hired because the Dean was a born-again Christian and a new dean, and he thought, 'I really, really ought to do something to inspire these students'. Maybe it could be a requirement to go to chapel every day, but maybe literature in a kind of Matthew Arnold way would do the job for him, so he hired me.²¹ The biggest surprise of my life was arriving at Northwestern where people saw the new position as a plum: 'We have someone who is useless, who is irrelevant and in literature, and we kind of understand how to put her to use; we will enjoy this.' And beyond that, to have students choose that medical school not because of me but because of the whole medical humanities programme is just a constant delight.

Hudson Jones: The Institute for the Medical Humanities at Galveston started somewhat differently and originated with, actually, the administrators of the medical school, including an influential dean named Chauncey Leake.²² They were very forward looking; they really wanted to try and bring to Galveston, the original medical school of the University of Texas, at least some of the kind of intellectual stimulation that medical students might have had by osmosis

²⁰ Association of American Medical Colleges (1984).

²¹ Matthew Arnold (1822–1888) was an inspector of schools in England, a literary and social critic, and a poet. As an education critic and reformer, he advocated the integration of English language and literature into secondary school curricula, influenced by his research trips as a schools' inspector to Continental Europe, and also the integration of the humanities more generally into the English education system. Posthumously, he is regarded as an intellectual inspiration for the development of English literature programmes in higher education. See Arnold (1868); in particular pages 266–70. For a full biography, see Collini (2008).

²² See Brody (2014) and Burns (2003); pages 233–6 on the evolution of the Institute for the Medical Humanities.

if they were in Austin – you have to understand that the main campus of the University of Texas is in Austin and the University of Texas Medical Branch is in Galveston; they're about 225 miles apart.

Hurwitz: And it's an island, isn't it?

Hudson Jones: A barrier island, right. It's the first offshore medical school, if you will, that I know of. Anyway, they began with the history of medicine. They hired Chester Burns, who was an MD but also a PhD in the history of medicine, to come to Galveston in the late 1960s, and his task or his role was to talk about history of medicine to anyone who would listen, basically.²³ And he was seeking out places, there wasn't any real curricular time, this was for the faculty physicians as well as for the students. So just working away at trying to add this historical awareness and consciousness to the entire medical school there was his job. And then he persuaded them to allow him to hire Tristram Engelhardt a few years later. Tris Engelhardt has an MD also and a PhD in philosophy of medicine.²⁴ The two of them worked together for several years, and when they began teaching they had history of medicine courses and philosophy of medicine courses, or medical ethics as the students always called them. The two of them then wrote a National Endowment for the Humanities programme grant and submitted it, in the early 1970s I guess it would have been, and received what was at that time a huge amount of money, \$500,000. And Chester Burns knew how to stretch his monies, so he began to hire additional people, but in history and philosophy. Then, I think because Jo Trautmann was at Penn State and because Kathryn had come to visit and was in literature, they established a position in literature and medicine. When I went there and began to ask what it was they had in mind, they didn't have anything in mind; they just thought they should have someone because Penn State did and Kathryn said so. So it was a wonderful opportunity to begin to explore what might work in that setting but it was a very different setting from Penn State, which was a brand new medical school where Jo Trautmann had literature courses. UTMB Galveston was already almost 100 years old as a

²³ Chester R. Burns (1937–2006) was the founder of the Institute for the Medical Humanities, in 1973, at the University of Texas Medical Branch, Galveston; James Wade Rockwell Professor of the History of Medicine, and Professor in the Department of Preventive Medicine and Community Health at UTMB. For his role in the formation and development of the Institute for the Medical Humanities at UTMB, see Burns (2001); in particular pages 11–12.

²⁴ H. Tristram Engelhardt, Jr, is Professor of Philosophy, Rice University, Texas; <http://philosophy.rice.edu/content.aspx?id=90> (visited 3 March 2014).

medical school and the curriculum was very tough to work your way into, and the only course that we had was a required course in the first year of the medical school, which was neatly divided into history and philosophy. So the task for me was to begin to find ways that literature worked in that course and that setting, and it was amazing. My colleagues, despite Chester Burns' commitment to this, were resistant, but when we began to use works of literature in teaching this course the students' response was so extraordinary that all resistance really just faded very shortly.

Hurwitz: The way that you tell this seems so utterly different from the kind of medical scenario that was established in the UK at that time. I mean I can, and we will obviously broaden this out to other parts of the world too in a minute, but thinking at that time, and probably the most important development in the 1960s was the Royal Commission on Medical Education, the Todd report, which did a number of quite important things: it established postgraduate training on a much more formal and geographically regional basis than previously and it led to the development of departments of medical sociology in the UK, and later on perhaps related, although not directly so, medical ethics too.²⁵ But I can't think of a setting as self-consciously experimental as you indicate. I don't know if that's true of anywhere else that anybody knows of? That sort of, 'let's try these different kinds of disciplinary mixes and see if we can make them educationally work'. At Hershey I understand there was a similar commitment to the community, primary care; it was in a rural setting and that seemed to be a component thread in the decision to establish a department of humanities.

Dr Andrew Elder: I would have thought that the influence of Michael Balint in the late 1950s and 1960s in the UK was similarly innovative and experimental.²⁶ It was not institutionally grounded. Well, it was to a certain extent because it was based at the Tavistock Clinic, in London, and was an exploration into bringing psychoanalytic thinking and medical practice together, and very influential too at that time, notably on the early attitudes and educational stance of the newly founded College of General Practitioners in introducing group work and in

²⁵ Royal Commission on Medical Education (1968).

²⁶ Dr Michael Balint (1896–1990) was a psychoanalyst based at the Tavistock Clinic, London and at the Department of Psychological Medicine at University College Hospital, London. His influence on the postgraduate education of general practitioners in the UK during the 1960s is discussed in Reynolds and Tansey (eds) (1998), and his influence in undergraduate medical education is discussed in Reynolds and Tansey (eds) (2007). See also Appendix 2, pages 77–8.



Figure 5: Dr Andrew Elder

being an interdisciplinary project.²⁷ I mean his first major work was published in 1957 and his influence, as well as other publications, has continued in many ways since that time.²⁸

Hurwitz: At what point, Kathryn and Anne, did you begin to think that some configuration around ideas of narrative and storytelling in healthcare/medical education might be a critical node in the ideas and concepts that you wished to work on, in terms of your teaching or your research?

Montgomery: Well there were no patients – maybe there are these days – but back in those days when I began there were no patients in medical textbooks and so that was a strong influence. Maybe there were kind of sketchy cases of one sentence but that’s all, not rich stories. So it was immediate, the usefulness of literature.

Hudson Jones: My teaching was very different at the beginning because of the way in which I’ve described that course and because of the need to find pieces of literature that really did enrich the kind of ethical issues and clinical ethics concepts that were being taught. So it was very much utility driven in a certain sense. But

²⁷ The Royal College of General Practitioners (RCGP) was founded in 1952. For a history, see the RCGP’s ‘History, Heritage and Archive’ page on its website; <http://www.rcgp.org.uk/about-us/history-heritage-and-archive/history-of-the-college.aspx> (visited 17 September 2014).

²⁸ Balint (1957).

for me, I think the expanded development view began along with the beginning of the journal *Literature and Medicine* in 1982; I became the editor of that journal in its third volume.²⁹ But I can remember, in the very first volume, references to James Hillman, a piece of his called ‘The fiction of case history: A round’.³⁰ Help me if I’m misremembering but he was a clinical psychologist, I believe, and talked about restorying, listening to the stories of his patients and helping restory them, so that they would have alternative stories to use to try and break through the patterns that weren’t working.³¹ The fifth volume, which came out in 1986, was edited by Joanne Trautmann Banks and she called it *Use and Abuse of Literary Concepts in Medicine*.³² And I think, Rita, that was one of the first times that you published your work ‘To render the lives of patients’, right?³³ Where you had your medical students and residents write about their patients? So that was a kind of breakthrough volume, and it really began to get all of us thinking in different ways.

Hurwitz: What about elsewhere? We’re focusing very much in the US at the moment. What about developments elsewhere at this time?

Professor Arthur Frank: Maybe I can just also talk about a couple of other things that were going on in the USA? I was then a graduate student finishing my dissertation at Yale in 1975 and trying to write about illness experience, particularly of dying. What was fascinating to me was that medical sociology had, again, no category for the actual experience of being ill. They did epidemiology, they did professionalization of medicine, they did organization of hospitals but what to me was the core of it, which was being ill, simply wasn’t on the academic agenda at that point. And academia was fragmented enough so that really I can’t feel guilty about not knowing what Kathryn and Anne were doing. These were very disparate sectors and you just didn’t have the networks you’ve got today that would have brought this onto somebody else’s radar. I was then trying to use, back in the mid-1970s, spousal narratives – memoirs of accounts of the death of a spouse. Simone de Beauvoir’s *A Very Easy Death* was a crucial text for me.³⁴ And

²⁹ For the full journal, see Allen Rabuzzi (ed.) (1982).

³⁰ Hillman (1975).

³¹ James Hillman (1926–2011) was a psychologist and therapist, primarily working in the Jungian tradition. See Kidel (2011).

³² For her editorial commentary on the fifth volume of *Literature and Medicine*, see Trautmann Banks (ed.) (1986).

³³ Charon (1986).

³⁴ de Beauvoir (1965).



Figure 6: Professor Arthur Frank

the point of the story at this stage was that I had to basically quit doing that work for more than a decade because there just wasn't any collegial, or publication, or other support for doing it. I found myself very much in a vacuum. But the other name I would bring into it, although it's unfortunate how things went later, was Elisabeth Kübler-Ross.³⁵ This was in the early 1970s before she had become a pop culture figure, and literally everything had been turned into 'five stages' of whatever, the intervention that she and her colleagues did at the University of Chicago, of bringing patients into grand rounds and focusing the rounds on their accounts of their experiences was radical and inspirational to me.³⁶ Now,

³⁵ The theories of psychiatrist Elisabeth Kübler-Ross (1926–2004), on terminally ill patients' experiences of dying were first published in 1969 and subsequently became widely implemented in palliative healthcare practice in Western medicine as the 'five stages of death': first stage, denial and isolation; second stage, anger; third stage, bargaining; fourth stage, depression; fifth stage, acceptance. See Kübler-Ross (1973); for her initial consultations with terminally ill patients at University of Chicago Billings Hospital, see pages 19–33. For a scholarly analysis of the influence of Kübler-Ross' theories on the hospice movement, and a study of the methodological limits of her research, from the perspective of thanatological and clinical research protocols, see Chaban (2000). See, also, a biography on page 84.

³⁶ For a popular critique of the appropriation, interpretation, and wide influence of Elisabeth Kübler-Ross' writings and theories on healthcare in the USA, see Königsberg (2011), in particular pages 8–12, 83–103. See also Kübler-Ross (2005).

ethics issues have been raised around this, that there are all sorts of problems with it, but what should be on record is that, for a graduate student in the early 1970s, the idea of an account that truly centered on the words of the patient, we need to honour Kübler-Ross for that. But then, for me, the story drops off for at least another decade because it was pretty disparate. People like Anne and Kathryn, my sense is you were functioning not entirely in a vacuum but in a very small, loose network.

Hudson Jones: Just a quick follow-up to the mention of Elisabeth Kübler-Ross. Larry Churchill, who was invited but was not able to come,³⁷ did a really fascinating article responding to what then became the misuse of Kübler-Ross' work where people thought, 'Well if physicians and nurses and others, if we can't help people who are dying stay alive, then by God we're going to help them die the right way and get them through the stages.' Larry Churchill's article was 'The human experience of dying', and he wrote that from his work with oncology patients who were dying – his training was in religious studies.³⁸ I just think it was one of the best articles that came from that trajectory from Elisabeth Kübler-Ross, and it brought his work to the fore. He very much was working, as she had been, with dying patients. It's not that she was wrong in what she was doing, it was that people were wrong in the way in which they were too simplistically applying her work.

Frank: Again, just very briefly, I think one of the tensions that you can see right there, which to me reverberates through so much of the work, all the way through, is between the responsibility that academics have to somehow synthesize material, to do something more general with the particulars versus the commitment of all of these different strands, to staying with the particulars. I think we'll see that an underlying tension for many of us is that we got into this work because we felt that how our own discipline was proceeding had gotten too far from the particulars of individual experiences. But, in order to give lectures, in order to publish, in order to do something with the material we come up with in various kinds of categories, and I keep Kübler-Ross there as a constant cautionary tale, because I certainly feel like I'm always hovering on this edge of how do I do more than just report particulars and leave it at that level without violating the whole reason why I got into it in the first place?

³⁷ See biography on pages 80–1.

³⁸ Churchill (1979).

Professor Jane Macnaughton: I just wanted to respond to that as a reflection really about the issue of the particular and the generic, and questioning whether the fact that you as sociologists, as literary people who came into a kind of medical culture, which very much forced you into that way of thinking and way of presenting. Is there a desire to be acceptable and accepted within that clinical bioscience culture, which forces us, in a way, to start to present the particular in these kinds of ways?

Montgomery: Luckily we're very poorly trained in all those generalizing techniques if we've been educated in literary studies. When I got my three-year grant from the National Science Foundation in 1983 to study narrative in clinical medicine, my colleagues in the preventive medicine department said, 'So you're going to set up a typology and count the number of stories?' And I thought, 'Shall I do that? I don't know how to do that'. So I just was brave and said, 'No, I'm just going to describe what's out there. I'm going to do a descriptive study and someone else can do the sociological study'. The descriptive study is really all I think needs to be done. So we were kind of resistant to that generalizing. Maybe later we'll take up this same general and particular issue with regard to medical ethics at the time, which was very generalizing and rule-based, principle-based, and the emphasis in the US hardly had a sense that people in literature were contributing to moral discourse because we didn't have rules and principles. Nor did doctors, you know. One of the first things I heard from a philosopher, the aforesaid Dan Clouser, was: 'You ask a doc what principle he's working on: he can't tell you. He must not have any principles.'

Hurwitz: We're still hovering around the 1970s at the moment and at that, pretty much 1973/4. Speaking for myself, and I'm not going to bring too much in but it seems relevant, is the year 1974. I read *Awakenings* by Oliver Sacks.³⁹ And the following year I read his book on migraine, which I think was before *Awakenings* was published.⁴⁰ I suppose I bring this up simply because it's not grappling with ethics explicitly but it is placing before the public a very particular view of the importance of narrative description and narrative accounts in clinical medicine. I don't know whether that was an influence or a dis-influence on anyone? Of course, it raises questions about the particular and the general as well, which is something that Sacks has often been asked about.

³⁹ Sacks (1973). Oliver Sacks (b. 1933) is a neurologist and writer. Since 2012 he has been Professor of Neurology at the Comprehensive Epilepsy Center, New York University; <http://epilepsy.med.nyu.edu/faculty-staff/neurologists/epileptologists/oliver-sacks-md#sthash.vpKyBiY.dpbs> (visited 3 September 2014).

⁴⁰ Sacks (1970).

Frank: The other book I want to bring into that is Sacks' *A Leg To Stand On* because, again, given what is crucial to me in all this, which is patients speaking for themselves about their experiences, I think that book really deserves to be recognized as somewhat seminal.⁴¹ Here was someone who was, in effect, deconstructing his medical training through the lens of his experience as a patient and giving one of the finest grained, phenomenological accounts of the experience of illness in its embodiment. When Sacks quits writing in the third person, observing patients as richly as he did and turns the lens on himself, I think we get the distinctive turn of a truly reflective medicine even more, rather than just simply an expanded clinical gaze.

Hurwitz: I think that's in the 1980s. For me, part of the importance of Sacks at that time was his recognition that case histories can be narrated in many different ways that have a bearing on a reader or listener's attention, evaluation of the important elements in a case, reasoning, and thoughts and feelings for a sufferer. At the time, I went back to read Freud's case histories and *New Introductory Lectures*.⁴² I personally went back to Luria and I knew others who were doing so too.⁴³ I was part of a cohort of students who were interested in this whole area but we had no term for it. We certainly did not call it 'narrative something', on the contrary we thought of it as forms of writing. I don't know whether that was a widespread phenomenon in other medical schools and other medical students.

Elder: It's rather nice to be reminded of *Awakenings*, and no book had greater influence on me, I think, as a young general practitioner at that time. It was because of its extended and beautifully written descriptions of clinical states, but it was also about the scrupulous, respectful, modest observation of the usually unobserved. That had a huge impact on me as a young GP.

⁴¹ Sacks (1984).

⁴² Sigmund Freud (1856–1939), psychoanalyst and Professor of Neurology, Vienna University (1902–1938). See Freud (1955) and Freud (1974). Professor Brian Hurwitz elaborated, 'Case construction and case-based reasoning have since become an important focus of the study of narrative practices in medicine. A major stimulus for this work was also Kathryn Montgomery Hunter's volume *Doctors' Stories* and the collection of papers published by the journal *Literature and Medicine* in 1992.' Note on draft transcript, 15 July 2014. See Montgomery Hunter (1991); Trautmann Banks and Hunsaker Hawkins (1992): whole journal. For further references to the topic of case histories/reports, see Professor Brian Hurwitz' notes in the archives of this meeting at the Wellcome Library, London, Archives and Manuscripts, reference GC/253.

⁴³ Alexander Luria (1902–1977) was a Russian neuropsychologist. See, for example, Luria (1972). A retrospective of Luria's work and his international influence is detailed in two dedicated issues of the journal *Neuropsychology Review*. See Tupper (ed.) (1999).

Montgomery: I'd like to add that *The Lancet* in the late 1970s, and certainly the 1980s, had accounts by patients of their experience, not quite rising to Oliver Sacks' quality but still a regular column. Does anybody remember that?

Hurwitz: The *BMJ* had a column called 'Personal View' for a number of years.⁴⁴

Montgomery: Was that it? Yes, anyway, it was a thing that was happening in the 1980s.

Professor Jens Brockmeier: I would like to add a little flashlight from a different world, from Continental Europe, because you, Brian, mentioned Freud. Of course, for people like me, for people of my generation, Freud was a very inspirational figure for a non-positivist, non-biomedically reductive approach to the human being in the world. This actually was the case for much of what happened in 1968 in the academic scene, and not only there. Habermas, one of the intellectual protagonists of those years,⁴⁵ in a famous discussion of



Figure 7: Professor Jens Brockmeier

⁴⁴ The 'Personal View' articles in the *British Medical Journal* were written predominantly by doctors rather than patients, based on a range of samples viewed in the 1970s and 1980s.

⁴⁵ Jürgen Habermas (b. 1929) is a German philosopher and social theorist who is associated with the legacy of the 'Frankfurt School' of philosophy. See, for example, Finlayson (2007).

Freud's work, spoke about the positivist self-misunderstanding of Freud,⁴⁶ because Freud always felt and thought and believed and hoped that he could turn psychoanalysis into a science and a proper biomedical discipline, so that medicine as an institution would accept his own work, possibly even himself, a Jew, as a member of the Viennese academic and bourgeois establishment, which, as we know, never happened. On the contrary, he had to flee from Austria in 1938.⁴⁷ The idea that psychoanalysis could turn into a 'real science' was a kind of misunderstanding, as Habermas and then also Ricoeur pointed out, because what Freud did was a novel way to examine human lives through life stories, histories, narratives.⁴⁸ What he did was analyse *fallgeschichten*, meaning both case stories and case histories, and in this way offered an alternative to established psychiatric doctrines and, even more, to today's biomedical psychiatry and neurology.⁴⁹

I should add that this issue was part of a larger debate in the 1950s, 1960s, and 1970s among those who were searching for a non-positivist way to understand the human being in the world. The one big tradition in Continental Europe – I'm not only speaking about Germany, Austria, and Switzerland but also about France and Italy – was of course a psychoanalytically oriented, holistic approach to the human condition.⁵⁰ Freud's work was of great importance for the student movement in the late 1960s, and its critical, anti-positivist momentum. He was also important for the attempts of many to come to terms with Germany's fascist history. He and others had in mind a sort of technocratic scientist, even physicians, who was trained to view human beings as merely biological

⁴⁶ See Habermas (1971).

⁴⁷ See, for example, Clark (1980), pages 502–12.

⁴⁸ Paul Ricoeur (1913–2005) was a French philosopher who worked in the field of hermeneutics. For Freud's concept of 'life history', see Brockmeier (1997).

⁴⁹ For a discussion of *fallgeschichten*, see, for example, Freud's remarks about how the case 'history' and the case 'story' are combined in his psychoanalytical methodology, in his introduction to 'A Case of Hysteria' in Freud (1977), pages 45–8; see also note 42.

⁵⁰ Professor Jens Brockmeier wrote, 'This approach was also backed up by theorists from the Frankfurt School of critical theory. I mentioned Habermas, but in the first place I surely should refer to Adorno. For Adorno, the political phenomenon of fascism and Nazi terror was closely connected to a positivist stance in the field of science and philosophy.' Notes on draft transcript, 4 November 2013. Theodor Wiesengrund Adorno (1903–1969) was a philosopher of the Frankfurt School of critical theory at the Institute for Social Research, Frankfurt, Germany. See, for example, Adorno (2003).

organisms.⁵¹ In the same picture you have the concentration camp physicians.⁵² In the 1960s and 1970s, spectacular trials against such physicians took place, also some famous studies came out about the work and world view of these concentration camp physicians.⁵³ What kind of physicians were they? This was part of a larger debate with the tenor of the times: Well, there's a price to be paid for biomedical reductionism, particularly in the context of German and Austrian fascism. Thus the psychoanalytical tradition and part of the phenomenological and holistic tradition, in a sense, even psychiatry was often seen as an alternative – one alternative. Let me say one more word on this tradition of psychiatry. There's a specific tradition in Germany, Austria, and Switzerland that has viewed psychiatry and psychotherapy as a hermeneutic practice, a practice of interpretive and dialogical understanding. This goes back to Martin Heidegger and Karl Jaspers.⁵⁴ Jaspers, a physician and philosopher, was the tutor, friend, and mentor of Hannah Arendt.⁵⁵ For Heidegger and Jaspers, the hermeneutic approach was a kind of existentialist and humanist alternative to the way established medical schools conceived of, and treated, human beings.⁵⁶ The

⁵¹ Professor Jens Brockmeier added such 'technocratic scientists' viewed human beings 'as objects of experiments done in favour of some dubious higher purpose, mostly called truth.' Note on draft transcript, 4 November 2013.

⁵² See Weindling (2004), in particular pages 88, 94–7, 100–3 for discussion of the trials of physicians from Dachau, Hadamar, and Ravensbrück concentration camps. For an account of an infamous concentration camp physician, Josef Mengele, see Lifton (1986), pages 337–83. One physician-prisoner testimony that was widely published is that of Dr Miklos Nyiszli, the chief physician of the Auschwitz crematoriums who worked under Dr Mengele; see Nyiszli (1962). For accounts of physicians and research scientists who were tried at Nuremberg, see Mitscherlich and Mielke (1962).

⁵³ From 1963 to 1965 the trial of physicians accused of committing war crimes at Auschwitz-Birkenau concentration camp took place in Frankfurt, for example; for the trial verdicts of specific doctors, see Fertig (1986), part one, pages 234–44. There is an extensive literature on this and related topics: an overview is provided in Nicosia and Huener (eds) (2002).

⁵⁴ Martin Heidegger (1889–1976) was Professor of Philosophy at the University of Freiburg. Karl Jaspers (1883–1969) was Professor of Philosophy at the University of Basel (1948–1961). See also, for example, Biemel and Saner (eds) (2003).

⁵⁵ Hannah Arendt (1906–1975) was a German-born philosopher, and political theorist. For a biography, see Young-Bruehl (2000). See also, for example, Arendt (1958).

⁵⁶ See Heidegger (1967) and Jaspers (1913). Professor Jens Brockmeier wrote, 'Jaspers was originally trained as a physician before he dedicated himself to philosophy. Several editions of his psychiatric textbook *Allgemeine Psychopathologie* [General Psychopathology] were published even in the second half of the 20th century, influencing many phenomenologically orientated psychiatrists. There were many connections between Heidegger and Karl Jaspers, philosophically and personally, until Jaspers broke with Heidegger on his commitment for the Nazi regime.' Email to Ms Emma Jones, 20 August 2014. Alan Olson notes, 'Although [Jaspers] rarely refers to his philosophy as hermeneutical it is hermeneutical throughout ...', in Olson (1979), page 117.

Swiss psychiatrist Ludwig Binswanger, a friend of both Freud and Heidegger, was a successful practitioner of a hermeneutic psychiatry.⁵⁷ His family was one of four generations of psychiatrists. They all worked in the famous Swiss hospital called Bellevue, a sanatorium where Ludwig Binswanger developed a sort of narrative therapy. Again, this was all meant to be an alternative to what they saw as the ‘scientific’ reductionism practised in the mainstream of their discipline. Psychoanalysis, in this context, was so important because it was not part of the academic tradition. It was, at least in the Continental context, an independent tradition.⁵⁸ In Europe, psychoanalysts had their own institutes, their own organizations, journals, conferences, etc. The medical tradition, in contrast, was academic, and basically ignored them, or better, there was a kind of mutual ignorance. For most biomedically trained physicians, psychoanalysis, with all its hermeneutic claims and narrative fantasies, was simply not part of scientific medicine. It was something beyond that, but it was always there as an independent tradition and, perhaps, even an alternative option. Only recently it seems to have had an influence on mainstream medical discussions. Interestingly enough, the discovery of narrative’s significance plays an important role in this rapprochement.

Hurwitz: Yes, I think that’s very interesting. There were one or two Continental physicians, as you put it, who came to London, not least Michael Balint himself but others, Heinz Wolff and others who were clearly very influenced and to some extent practised psychoanalytically informed psychiatry.⁵⁹ I remember as a medical student at UCH (University College Hospital), just down the road, seeing a patient – this is an illustration in a sense of what you’re saying – a young man, being presented with apparently total paralysis apart from breathing and being able to eat and chew, who was thought to be hysterical. And the neurologists, this was during a grand round in neurology, actually said: ‘Don’t tell the psychiatrists, don’t let anyone know.’ In fact, they asked people to close the doors and make sure that there were no psychiatrists informed that this patient had been admitted, on the grounds that he would never get better if he was referred to the psychiatrists. He was treated with physical therapy,

⁵⁷ See, for example, Binswanger (1946). See also Frie (2010).

⁵⁸ Professor Jens Brockmeier elaborated: ‘[Psychoanalysis had] a strong hermeneutic component, which, over the last 20 years, has been rediscovered especially by intersubjective, dialogical, and narrative approaches in North American psychoanalysis.’ Note on draft transcript, 4 November 2013.

⁵⁹ Heinz Wolff (1926–1989) was Consultant Psychotherapist at the Maudsley Hospital, London. For an obituary, see Anon. (1989).



Figure 8: Professor Rita Charon

physiotherapy and encouragement, but that sense of antipathy and suspicion between physical and psychological medicine was pronounced when I was a medical student, even in an enlightened institution such as UCH. I never really heard Freud being really discussed in my own medical school.

Shall we move on a little towards the question of the relationship between narrative formulations and ethics, which has been mentioned? Medical ethics in North America and in the UK was a field that was beginning to stir in the late 1960s and 1970s, and grow in the 1980s.⁶⁰ I'm interested to know about the interaction between narrative theory and medical ethics.

Professor Rita Charon: Maybe just before you make that turn, what we've been listening to so far, what we've been doing so far is kind of a US and UK, or Continent, divide in how these things came up. There was also the humanities–medicine divide and just to complete the sources of this, the impetus or the need for extending the medical education to include humanities came in part from the inside of how horribly missing the medical students found their education to be. Missing of the singular; it was exactly that. I was at Harvard from 1974 to 1978 and we had to go way out of our way as students to find professors who

⁶⁰ In the 1960s, the Nuremberg Code, adopted as the Declaration of Helsinki in 1964, is widely considered to have been the context for the development of medical ethics in clinical practice; WMA (1964). For the 1970s, see Beauchamp and Childress (1979); Campbell (1972), and note 130. For the 1980s in the UK, see British Medical Association (1988).

could teach us. So we hired Ned Cassem, the Jesuit psychiatrist at Mass. General Hospital, to come to Countway and teach us something about caring for dying patients because it wasn't in the curriculum.⁶¹ And it was through sociology, that's where I found Elliot Mishler.⁶² Elliot Mishler was my entry into English literature. As a sociologist, he was studying the linguistics of the doctor–patient conversation, and his 1984 book *The Discourse of Medicine* was the first elegant study of the voice of the life world and the voice of medicine and how they contradicted one another.⁶³ Elliot is the one who saw me through medical school. We recognized different lapses from within and without the medical world, and we were all just hungry for something other than, you know, Franny Moore brings a patient after a hernia operation into a grand rounds at the Brigham,⁶⁴ takes off the sheet and says, 'Bear down for us, Mr Right' and the naked man was supposed to bear down and show us his bloody hernia. And we all objected to that and said, 'No, no, you can't do that in our names' and he literally, Franny Moore, the big chief of surgery, pats us on the head and says, 'You'll learn'.⁶⁵ So these were different forces and we were just starving for some kind of corrective, we didn't know the word positivist yet but that's what it was [laughs].

Macnaughton: I'd like to echo that point from the UK perspective. I came in as a medical student having done history and English in 1982 in Glasgow and was profoundly shocked about the transition between those two ways of thinking and understanding and almost instantly vowed that I would try and do something about it. But the kinds of things we did was we got involved in voluntary literary reading groups.

This was Robin Downie and Ken Calman as well who helped to host these groups for us, and that's what started off a trend in Glasgow.⁶⁶ I was profoundly shocked when we were introduced to our first real patient, not a corpse, and one

⁶¹ Dr Ned Cassem was Chief of Psychiatry from 1989 to 2000 at Massachusetts General Hospital; <http://www2.massgeneral.org/allpsych/history100.asp> (visited 4 March 2014). Countway Library of Medicine, Boston.

⁶² Elliot Mishler is Professor of Social Psychology, Department of Psychiatry, Harvard Medical School; <http://www.hup.harvard.edu/results-list.php?author=2369> (visited 17 September 2014).

⁶³ Mishler (1984).

⁶⁴ Peter Bent Brigham Hospital, Boston, Massachusetts, USA.

⁶⁵ Moore (1995).

⁶⁶ During this period at the University of Glasgow, Robin Downie was Professor of Moral Philosophy and Sir Kenneth Calman was Professor of Oncology. See Reynolds and Tansey (eds) (2007), pages 23 and 40.



Figure 9: Professor Jane Macnaughton

of the students asked our clinical teacher, ‘What do I say to the patient?’ And I said, ‘Well, surely you just introduce yourself and say hello.’ I mean it’s a kind of normal meeting of a person that you’re doing here. But the problem was in that culture, everything was formulaic, everything had to be taught to be done in a particular kind of way. Even that very minor point shocked me profoundly.

Hurwitz: When I was studying medicine in London in the 1970s, actually from the 1960s onwards, the London Medical Group held regular meetings that were relatively informal for raising ethical issues in medicine.⁶⁷ It was funded by the Institute of Medical Ethics, ostensibly to focus on ethics.⁶⁸

Frank: I was just going to add – for the historical record it really needs to be added – Rita and all of us in this corner, at least in our generation, it goes

⁶⁷ The London Medical Group (LMG) lectures began in 1963 and continued until 1989. See Reynolds and Tansey (eds) (2007), pages 11–15, 36–7, 44, 54 and 71–119 for details of the LMG and regional groups and topics for these lectures.

⁶⁸ Professor Brian Hurwitz wrote, ‘[The focus on ethics was] within a broad frame which included, aspects of the politics of health, healthcare funding, Ivan Illich’s critique of western medicine and humanistically informed new practices, such as giving the parents of still births the dead baby to hold and to name, practices informed by all sorts of different concerns and included components of psychoanalytically informed thinking.’ Note on draft transcript, 24 October 2013.

without saying but it needs to be said: universities had gone through an absolute sea change in the late 1960s and early 1970s and the divide that Rita has just described to us between the attitudes of the professors and the attitudes of the students.⁶⁹ I think of the influences of the feminist movement and the Black Power movement and a lot of the things that are brought together under this difficult and troublesome label ‘identity politics’, which has its negative side as well as its positive side.⁷⁰ But the attention to the kind of ethical issues that Rita was just referring to, Jane was just referring to in a different way, this is all situated within the politics of the day, and the sense we had as students, at that point, that we really understood something our professors didn’t understand and it was incumbent on our generation to bring into the institutions something that was sadly lacking before. I say that because I’m not sure that’s true today. I’m a little troubled that my students don’t seem to have that same sense of, ‘Oh, have you guys ever got it wrong and good thing we’re here to straighten it out.’ But for Rita, Kathryn, and me, for us the origin, going back to the civil rights movement, when all of us were growing up, what’s absolutely crucial is the kind of consciousness that then would be brought to these clinical medical issues.

Hurwitz: Yes, I think some of that context influenced the London Medical Group’s deliberations.⁷¹

Macnaughton: There was a series of medical groups. There was a Glasgow medical group and I just can’t remember what they were about but they were obviously important.⁷²

Hurwitz: Well, what we talked about in London were all sorts of things: poor pain relief; NHS (National Health Service) birthing practices; the validity of IQ testing; how to help parents cope with a stillbirth; whether there were distinct

⁶⁹ See, for example, Altbach and Cohen (1990).

⁷⁰ For a history of the feminist movement in the USA see, for example, Gilmore (2008). For a UK-based contemporary perspective see Rowbotham (1969). For the Black Power movement in the USA see, for example, Ogbar (2005). For a discussion of the problems of the term ‘identity politics’ and arguments for alternatives, see Nicholson and Seidman (eds) (1995), pages 1–35.

⁷¹ Professor Brian Hurwitz elaborated: ‘Although the impetus was on developing medical ethical thinking, the foci of interest of its meetings were often much wider; they were set by committees of medical students which decided which speakers would lead discussion, and as well as picking up on medical controversies of the period, the topics and agendas tackled were stimulated by social issues, including the hierarchical and authoritarian nature of medical organisations.’ Note on draft transcript, 2 September 2013.

⁷² See Reynolds and Tansey (eds) (2007), pages 21–2.

stages of bereavement. Issues that came to the fore as a result of what today we might refer to as ‘contested narratives’ – a term not then in use – accounts strongly dependent on viewpoint and value where these could differ or even contradict each other depending on whose voice was being heard.

Macnaughton: I do remember that now and that was one of the things that galvanized us, particularly in the Scottish universities, to get together. I remember we actually, as students, became committee members on this group and it was largely about ethical issues and I remember we had a debate about the ethics of pharmaceutical companies, that kind of thing. We were quite vocal and then we got together across universities and had a meeting. So it was a focus actually for that kind of thinking amongst the students at that time.



Figure 10: Dr John Launer

Dr John Launer: Like Jane, I came into medicine with an English degree and I had a rather strange experience in the early-to-mid 1970s, which was I found myself being taught by quite radicalized sociology lecturers. This was the first generation of sociology lecturers who were very much influenced by Ronnie Laing and David Cooper and anti-psychiatry, and I was immensely sympathetic to them.⁷³ I found myself among a very small minority of medical students who were. I just wanted

⁷³ Laing (1960); Cooper (ed.) (1967). See also, for Cooper, Wall (2013), and, for Laing and the anti-psychiatry movement in Britain and the Netherlands, Jones (1998).

to introduce that thread, that there was also a strand of what I would regard now as quite reactionary medical students trying not to be influenced by radical anti-psychiatrist sociologists, who were taking us off to try and have intelligent conversations with patients with a diagnosis of schizophrenia in the asylums, just before they were being dismantled,⁷⁴ and meeting with tremendous resistance from the majority of medical students. So that's a paradoxical thread running alongside the general trend that's been described.

The other thing I'd like to mention is the early emergence in the 1970s of patient support groups.⁷⁵ One of the things I did at medical school was, I was very involved in the foundation of the National Eczema Society (UK), which was one of the first, and later became one of the largest, self-help groups, and that was the first forum I can remember where patients and families were talking very assertively about their own narratives, their own personal experiences and quite definitely pitching that against the medical construction of the world for the very first time.⁷⁶ Later there was an interesting phenomenon that I think they got subverted by the pharmaceutical industry, and they started to represent very different interests, but the early meetings, certainly in the Eczema Society, the Psoriasis Association (UK), and other self-help groups were quite literally meetings in the front rooms of families who were afflicted by these disorders, just telling each other their stories.⁷⁷

Hurwitz: Yes, that kind of discussion clearly has a storytelling component. Was it at the time framed in those terms? For example, a work such as *The Doctor, the Patient and his Illness* is predicated on doctors developing and discussing stories of clinical practice, yet the word 'narrative' is not used once in the text.⁷⁸

⁷⁴ Barham (1997).

⁷⁵ See, for example, Mold (2010), and for discussion of various patient groups' emergence in the UK and USA from the 1960s to 1980s, see Wood (2000), pages 36–9. The Patients Association (UK) was founded in 1963; its records are available in the Wellcome Library, London, Archives and Manuscripts, SA/PAT. See also note 130.

⁷⁶ 'Formed in 1975, the National Eczema Society has two principal aims: first, to provide people with independent and practical advice about treating and managing eczema; secondly, to raise awareness of the needs of those with eczema with healthcare professionals, teachers and the government', quoted from the National Eczema Society's website; <http://www.eczema.org/about-us> (visited 4 March 2014).

⁷⁷ 'The Psoriasis Association was founded in 1968 by Dr Dick Coles – a Consultant Dermatologist at Northampton General Hospital', quoted from Association's website: <https://www.psoriasis-association.org.uk/pages/view/about-us/history> (visited 4 March 2014).

⁷⁸ Balint (1957).

Similarly, we recognize narrative impulses behind the founding of the first patient organization, the British Diabetic Association by H. G. Wells in 1934, but its purposes are not explicitly framed in terms of narrative.⁷⁹

Frank: What John is saying has a parallel to what was going on in sociology. Talcott Parsons, who was tremendously influential – if a sociologist was influential in medical schools in the 1960s and 1970s, it was Parsons – railed against what he would have called ‘patient collusion’.⁸⁰ In his view, for patients to talk to each other was the worst thing in the world because they would reinforce each other’s ‘secondary gain’ of being ill. When John is talking about these support groups, you forget today exactly how radical a move that was at that point. It was going directly against what was accepted, theorized knowledge. Even when I was a cancer patient in the late 1980s, it was against the rules of the cancer centre for the Canadian Cancer Society to sponsor support groups, to advertise, put notices in elevators. So this didn’t go away overnight. And lest we forget, what John’s describing is a battle that continues really up until the turn of the present century.

Charon: From our point of view, you guys were the liberators. Those who brought into the medical institutions these ways of knowing and thinking and doing and reading that were not enclosed within the bioscientific universalizing replicable mode were like our liberators. Ned Cassem, not because he was a psychiatrist but because he was a Jesuit, was able to bring this illumination into what was otherwise a really repressive atmosphere.⁸¹

Montgomery: I used to use a metaphor of medical schools being an intellectual ghetto and that the job of the medical humanities was to, you know, find a way out or a way in, or it was an enclosed room and we opened a few windows, or maybe even just one window? People used to say to me, ‘Not every medical student wants to read a short story or a poem’, and truly, I believe this to the tips of my toes, that doesn’t matter. They might be interested in art theory, they

⁷⁹ [The British Diabetic Association] aimed to foster ‘the latent solidarity of people subject to a distinctive disorder [...] to enable them to gain common advantage in the exchange of opinions and experiences [...]’, quoted from http://www.diabetes.org.uk/About_us/Who_we_are/History/HG-Wellss-letter-to-The-Times/ (visited 20 November 2013).

⁸⁰ Talcott Parsons (1902–1979) was a founder member of Harvard University’s Department of Social Relations where he taught from 1945 to 1973; <http://oasis.lib.harvard.edu/oasis/deliver/-hua00002> (visited 15 September 2014).

⁸¹ See page 25.

might be interested in history, they might be interested in psychoanalysis, they might be interested in all sorts of things: religion, sociology, art, anthropology, culture – some view of medicine from the outside is very salutary.

Macnaughton: We might get onto this later but that kind of approach is one that I would like to strongly challenge now because I think that's the way in which Howard Brody in his article about the three characterizations of our field, and I can't remember just exactly what they were but I will be able to for the record,⁸² but it seems to me that the problem with that, if we are talking about a field that is trying to deliver a challenge to this positivistic way of looking at the world and understanding people, then taking that kind of piecemeal approach and saying, 'Well whatever you're interested in, just read it', it's not going to really present a kind of a fundamental challenge to the way of thinking that medical students are introduced to. So, for me that's the big challenge for our field now and into the future and that's why I would say that, I am going to be quite strong here because there are so many people involved in education. I think the education approach has been a failure. I think the only way, the way to do it now, and we'll see how it works, is through an approach to biomedical research and how we start to work alongside those who are engaged in that kind of research in order to challenge it to bring along a different way of thinking. Now, there are lots of problems with that because the humanities focus on the individual and the particular, and the sciences on the generic. On the other hand, the humanities viewpoint is holistic and it is difficult to bring that alongside an experimental approach, which is so atomistic. How do we bring those two ways of doing things and methodologies alongside each other and into conversation? That's a fundamental problem.

Hurwitz: Can we return to this important question because Kathryn just mentioned the term 'medical humanities', I think for the first time in this discussion. We're hovering around wherever we are, the mid-1970s, maybe mid-1980s. Are we thinking of the medical humanities as proto-narrative conceptions broadly construed? Does the creation of the Institute for the Medical Humanities in a sense provide the umbrella for what we think of today as narrative-based medicine or narrative ways of thinking about medicine?

⁸² Professor Jane Macnaughton wrote on the 'three characterizations', '(1) The idea of the liberally educated person, 2) educating the judgement for those involved in important roles in society and 3) humanities as a supportive friend to busy clinicians.' Note on draft transcript, 28 October 2013. See Brody (2011a).



Figure 11: Participants at the Witness Seminar

Montgomery: The Galveston Institute called itself the Institute for the Medical Humanities and the department, the medical school department at Hershey, Penn State was called the Department of Medical Humanities.⁸³ So that's been there from the beginning.

Hurwitz: Yes, 1967.

Montgomery: And I think, and I wish somebody could remember the Dean's name. It's George Harrell, who had several clever ideas, one of them was that department; the other was to place the library in between the classrooms and the hospital since he was building everything from the start. He made clinical students, he made all students, go through the library. [Laughter] But I think more recently, the windows that the medical humanities opened onto the enclosed room/torture chamber of medical education really may – I'd want to think about that farther – have all in common, this emphasis on the particular rather than the general, and a promotion of skills that can be described as hermeneutic; the skills of interpretation, making sense of things – all very valuable for future clinicians.⁸⁴ And if narrative has come to dominate it more recently, it's not because history can't do it as well, it's that history is perhaps less easy to teach in a new and different way that is better

⁸³ See note 11.

⁸⁴ For an overview of hermeneutics, see Forster (2007).

situated for practical, clinical students. History professors tend to teach history like history professors everywhere. You're laughing, Art, and I'm going to say, so do social scientists; they tend to not 'temper the wind to the shorn lamb'.⁸⁵

Brockmeier: I want to underline with a thick pen one word in your comment, Kathryn, the word 'hermeneutic' or 'hermeneutics', expanding a little bit this Continental stuff into this Anglo-Saxon world, even if this might provoke a reaction like: 'What do we have to do with that stuff?' We have in fact already addressed a number of important, shall we say background, developments, of what at one point became narrative medicine: literature, of course; the humanities; critical sociology of the 1960s and 1970s; the ethics discussions; the self-help movement; social linguistics; studying discourses between physicians and patients, among others. I think hermeneutics, too, is an important formation to keep in mind as one of these background movements. It is difficult to make this case, I have to admit that, it is difficult because, well, it's a philosophical thing and this is very far away from the world of most medical practitioners; and philosophically it's Continental philosophy, not analytic; that is to say it's even farther away, it's Heidegger, Gadamer, and Ricoeur.⁸⁶ But then, if you look at what protagonists of narrative medicine write – some of them are here today – you can find in their works many reflections and assimilations of the basic tenets of the hermeneutics of understanding and interpretation, developed by people like Ricoeur or Gadamer or Heidegger.⁸⁷ So take, for example, Rita Charon's *Narrative Medicine*⁸⁸ – I just re-read it to prepare for this meeting – Charon's main claim is that, and you all know her wonderful book, medicine is all about narrative, even if medicine is not aware of this, but there is hardly any aspect of the medical enterprise where you don't have people engaging in narrative practices. I would add that all these practices, as described by Rita in her volume, show that underlying them are indeed hermeneutic attempts to understand the human being, to understand the 'other'. If I look at my notes, I find questions such as: What are the underlying hermeneutic-interpretive operations of narrative medicine, or narrative-based medicine? Similar questions can be found in Gadamer and Heidegger and Ricoeur, who all wondered how we understand both the healthy and the sick

⁸⁵ A proverb listed in Herbert (1640), proverb number 867.

⁸⁶ Hans-Georg Gadamer (1900–2002) was a philosopher associated with the field of hermeneutics. See, for example, Gadamer (1976).

⁸⁷ For Gadamer and Ricoeur, see, for example, Gadamer (1991) and Lawlor (1991).

⁸⁸ Charon (2006).

human condition. Take the idea that narrative medicine is suffused with attention to the ‘other’; the sick one, the patient, and that this means it focuses on the understanding of meaning, of acts of meaning, and processes of meaning-making rather than presuppositions, or information, or biomedical facts. Next, there is this strong interest in understanding singularity, the single case. A couple of people have mentioned how important it is for the entire enterprise of narrative medicine to be aware that we are always concerned with singular individuals, singular diseases, singular treatments, with individual predicaments. Then, there is this concern with understanding otherness, understanding the other person, other physical and psychological ways of being in the world. Further, there is the interpretive imperative of hermeneutics, more specifically, in order to understand illness events and the individuals afflicted by them. We have not merely to interpret them but to do so from a number of different points of view. Of course, these interpretations are not final, definitive acts; they are unfinished, and unfinishable, ongoing processes.⁸⁹ In addition, we have to keep in mind that we are paying heed to, and critically interpreting, a multitude of often contradictory sources of authority. Maybe this marks one of the historical differences Art Frank referred to, distinguishing an attitude towards accepting authority before and after the 1970s: the acceptance of an authority.⁹⁰ Today, on almost all issues you have a number of different authorities making different claims, asking us to permanently engage in interpretive efforts. Now, is it for the clinician or for the care person to figure out what kind of authority is appropriate here?⁹¹ In her book, Rita quotes various vignettes from interviews and conversations that point out the existential charge, even of apparently minor decisions.⁹² More often than not, the issues at stake have existential gravity; they come with a lot of thinking and pondering on the known and unknown, on the consequences of all that is being decided in doctors’ offices. Narrative-sensitive medicine is there in doctors’ reading, writing, and interpreting of language, of texts ubiquitous in medical everyday life. Often

⁸⁹ Professor Jens Brockmeier elaborated: ‘[This] is another central hermeneutic conviction: the *openness* of interpretation.’ Note on draft transcript, 4 November 2013.

⁹⁰ Professor Jens Brockmeier added: ‘Over the last decades, it has become a widespread idea that scientists, physicians, and patients, in fact, every politically mature citizen can and must take a critical stance toward authority, any authority – which is a profoundly hermeneutic stance. Today, it’s difficult to imagine a different stance at all.’ Note on draft transcript, 4 November 2013.

⁹¹ Professor Jens Brockmeier added: ‘[They] are continuously confronted with diverging opinions. Decisions – and interpretations – have to be made of enormous scope, weighing up different authorities.’ Note on draft transcript, 4 November 2013.

⁹² See note 88.

these are complicated texts that include statements of patients, of other colleagues, charts, laboratory test results, scans, and photographs. These ‘texts’, understood in a broad sense, also report the ‘language’ of the body. That is, they are very complicated texts to be read and interpreted in the context of all the other stories – life stories, illness stories, healing stories – which then, eventually have to be made to cohere, to a degree that allows practitioners to act, at least until a new interpretation shows up. You have to become aware of the particular linguistic shape and that is mostly, in fact, of the narrative form and structure of this kind of understanding. It’s not the chart, but it’s your interpretation that is at the centre of this entire business.⁹³

Finally, just to mention two last hermeneutic *gestalts* of thought. One is what Gadamer calls the fusion of different horizons. This means you have to expand your own horizon as a clinical practitioner and fuse it with the horizon of someone else by empathically understanding the plight of someone else. You have to put yourself into the shoes of another, to read their mind and connect to their feelings. The other *gestalt* is the hermeneutic circle that we already mentioned implicitly a few times: the interplay between the whole and the individual part. Consider that patients and their caregivers enter whole, as Rita Charon put it, whole with their bodies and their lives into sickness and healing, their families and their beliefs, their values and their hopes, and therefore cannot be fragmented away from the deepest parts of their lives and selves – although this, of course, often happens. These, then, are principles of hermeneutics that you find, implicitly and sometimes explicitly, in the works of scholars of narrative medicine – Rita’s book is one example. I think it’s striking how influential the hermeneutic approach has been in the formation of narrative medicine in the last 20 or 30 years.

Hudson Jones: I just want to add two footnotes, if you will, to that. One is to Ron Carson, who came in 1982 as Director of the Institute for the Medical Humanities and who was director for 23 years before he stepped down.⁹⁴ He

⁹³ Professor Jens Brockmeier added: ‘It’s not the patient’s story, it’s not fact, it’s not fiction, but it’s the act of interpretation, the meaning that you give to it, that matters. And whenever things get complicated, this act of bestowing significance morphs into a narrative act.’ Note on draft transcript, 4 November 2013. For a discussion of this ‘morphing’ process, see Brockmeier (2013a).

⁹⁴ Ronald A. Carson is a founder/co-editor of the journal *Medical Humanities Review* (Institute for the Medical Humanities, University of Texas) and founding member of the editorial board of the journal *Medical Humanities* (Institute of Medical Ethics (UK)/BMJ). He is Professor Emeritus at the Institute for the Medical Humanities, of which he was Director (1982–2005), University of Texas Medical Branch, Galveston; <http://imh.utmb.edu/about-us/faculty/ronald-a-carson> (visited 14 March 2014).

was trained in the hermeneutic tradition and we all – faculty and students at the Institute – everything that you said, Jens, we’ve heard him say. So he, in the United States, was a transmitter of that tradition to many of us working in medical humanities or in literature, narrative, or ethics, whatever field. And I want to mention Kathryn’s book from 1991, *Doctors’ Stories*, because it was reading Kathryn’s book that helped me to articulate some of my own quandaries or struggles, to shape what I thought was happening between literature and narrative and ethics when we get there.⁹⁵

Hurwitz: Could I just ask Kathryn whether in fact your work at that time was drawing on their hermeneutical literature?

Montgomery: Yes, although I had to take the word out of the text or they wouldn’t publish it.

Hurwitz: Really?

Montgomery: No one would read it. This is Princeton University Press. It’s true, it’s true, it’s true, yes. [Murmurs from other contributors] No, it’s true. They wanted people to read it.

Hurwitz: Are we grappling here with the delineation of a sort of narratological apparatus in a period between the 1990s and 2000? Kreiswirth argues in his article in *Poetics Today* that: ‘Until relatively recently, formulating [...] say economic theory, jurisprudence or medicine in terms of narrative was not an available option. The production and dissemination of knowledge in these domains [...] were governed by largely scientific or quasi-scientific modes of enquiry and discourse, by non-storied forms of investigation and reportage. Narrative models were so far outside the disciplinary paradigms that they were literally inconceivable, at least as analytic tools. Story may have appeared in these contexts, but it would have been mobilized [...] only as digression, [for] example, or rhetorical ornament; something supplementary to rational argument, and not worth commenting on.’⁹⁶ Now, he says, ‘things have changed’. Is this swerve that Kreiswirth here writes about worked out in medicine through the development of a hermeneutic, narratological theory at that time?

Montgomery: I’m going to claim ignorance. This is what people who read do and therefore the hermeneutic, the interpretive act, is what readers do. People who study literature, study interpretation and have, even if they are pre-

⁹⁵ Montgomery Hunter (1991).

⁹⁶ Kreiswirth (2000), page 295.

theoretical – that is, they went to graduate school in the old days – we still have a lively vernacular theory, I guess Art (Frank) might call it, of interpretation. Hermeneutics is what readers do, it's what doctors do. So it was what people with a literary background, when they set out to observe medicine, noticed that their clinical colleagues spend their day doing, making sense of signs and, in their case, symptoms too. So you don't have to read the French narratologists to be trained in this.

Launer: I'd like to ask a question. I ought to know the answer and I'm ashamed of not knowing the answer but it's to do with the emergence of the specific word 'narrative'. We could be here talking about the history of hermeneutical medicine or interpretive medicine or restorying medicine but we're not, we're specifically talking about narrative medicine. I'm wondering when that swerve took place that someone actually decided, 'You know what, we'll use the word "narrative"'?

Hurwitz: Yes, when and how do research and teaching start to become condensed around narrative?

Charon: I remember one node in the chain. So my path was into medicine and, with the help of Elliot Mishler and others,⁹⁷ I kind of got through medical training not too damaged. Along the way I found out about the Society for Health and Human Values and went to a couple of those meetings.⁹⁸ I said, 'Oh my gosh, there are people here who know about literature? Who are interested in what doctors do?' But then what drove me to the English department was when I was on the junior faculty at Columbia sitting in these little clinics at the Presbyterian Hospital and understanding experientially that what these people paid me to do was something to do with what they told me; that I had to put together these conflicting stories from the patients, and the intern, and the neighbour, and the home attendant, and that's what my job was. And I said, 'I don't know how to do that.' And that's when I went to the English department because I found out about the Society for Health and Human Values and maybe there was some help from that department. I went and knocked on the door of

⁹⁷ See page 25.

⁹⁸ 'The Society for Health and Human Values (SHHV) was officially established in 1969 as a membership organization for persons committed to human values in medicine. [...] In early 1998, the SHHV along with the Society for Bioethics Consultation and the American [Association] for Bioethics merged to form the American Society for Bioethics and Humanities.' Quoted from the website of the Moody Medical Library, University of Texas, where the archival records of the SHHV are deposited; <http://www.lib.utexas.edu/taro/utmb/00079/utmb-00079.html> (visited 14 March 2014).

the English department at Columbia and they let me in as a graduate student. And it was when I took the introductory MA course in narrative theory that I started reading. I mean I had never read Aristotle, I had certainly never read Wayne Booth, and I certainly hadn't read Paul Ricoeur.⁹⁹ But it was then in a kind of theory requirement and it was narrative theory. Reader reception and all the other theories gave me a model for, 'I'm sitting in one chair, Mrs Dempsey is sitting in another chair: What are we doing together?'

I suddenly had all these urgently valuable ways of thinking about what I was doing there in the clinic, or in the emergency room, or up on the wards, or in attending rounds. So that's when I got my loyalty to narrative theory. I remember we got some money from the Kaiser Foundation.¹⁰⁰ I used half of it to pay for my PhD and the other half to get our Narrative in Medicine Circle. It was Kaiser Narrative in Medicine and so the Kaiser Foundation funded several meetings for Jo Trautmann Banks, Suzanne Poirier, Anne Hunsaker Hawkins, Anne Hudson Jones, Kathryn, Julie Connelly, Martha Montello, and me.¹⁰¹

Montgomery: I know we'd met before 1991 because that's when my book came out, at our last meeting, and Jo Banks actually said to me, 'You're not really in literature any more, are you?'¹⁰²

Professor Maura Spiegel: I can't say at what precise moment the word 'narrative' really takes hold in literary studies, but I date it myself to Hayden White's

⁹⁹ For Booth, see, for example, Booth (1988). For Ricoeur, see page 21.

¹⁰⁰ Established in 1948 and relaunched in 1991, the Henry J. Kaiser Family Foundation is a USA-based not-for-profit organization working in the healthcare field. For its 'History and Mission' see <http://kff.org/history-and-mission/> (visited 14 March 2014).

¹⁰¹ For Joanne Trautmann Banks see page 87. Suzanne Poirier is Professor Emerita of Literature and Medical Education at the University of Illinois and formerly Editor of the journal *Literature and Medicine*: <http://www.uiowapress.org/people/suzanne-poirier> (visited 15 October 2014); Anne Hawkins is Professor Emerita of Humanities, College of Medicine, Pennsylvania State University: <https://profiles.psu.edu/profiles/display/112829>; Julie Connelly is Professor Emeritus, University of Virginia: <http://www.medicine.virginia.edu/community-service/centers/biomedical-ethics-and-humanities/people/affiliated-faculty.html>; Martha Montello is Associate Professor, Department of History and Philosophy of Medicine and Director of Medical Ethics Education, University of Kansas Medical Center; <http://www.kumc.edu/school-of-medicine/history-and-philosophy-of-medicine/faculty-and-staff/martha-montello-phd-.html> (all websites visited 14 March 2014). For a later publication involving many members of the Narrative in Medicine Circle, see also Charon and Montello (eds) (2002).

¹⁰² See note 95.

book *Metahistory*, which I was reading as a graduate student in the 1970s.¹⁰³ White's argument, that history is a form of storytelling, that it follows particular conventions, had an enormous influence in the humanities.

Frank: The other person who really needs to be brought in here, the brief answer to your question, why the 'narrative' word, to me, first of all, is Rita. If anybody has really brought that word in, it's been you. But the other book that was hugely influential to me and I think did a great deal to bring narrative into the curriculum is Arthur Kleinman's *The Illness Narratives*.¹⁰⁴ I'm not sure when Arthur and Leon Eisenberg started their postdoctoral training programme at Harvard, but the students they were turning out, and right now as that department under a different name continues with Paul Farmer,¹⁰⁵ that's a whole other aspect of this that's really not represented in this room but that is very much part of the larger story.¹⁰⁶ For me, at that point I only had a couple of articles of Rita's – you hadn't published that much by the early 1990s. It was the availability in 1988 of Kleinman's *The Illness Narratives* that really showed me the possibility of writing a particular kind of book that avoided the problems of Kübler-Ross but nevertheless really, really put the experience of ill people at the centre of this. Kleinman and Eisenberg distinguishing between illness and disease led to my distinguishing between the ill person and the patient; this is very important. The point is that to do academic work, you need some kind of previous work to legitimate that, to be able to explain to chairmen and deans, and so on, what you're doing. Because Harvard was for Kleinman a kind of bully pulpit, he was then able to give this a cover that made a huge difference to the rest of us.¹⁰⁷ Arthur was, to me certainly, an extremely generous man at a time when I didn't know other people in the field.

¹⁰³ White (1973).

¹⁰⁴ Since 1982 Arthur Kleinman has been Professor of Medical Anthropology and Psychiatry at Harvard Medical School; http://www.fas.harvard.edu/~anthro/social_faculty_pages/social_pages_kleinman.html (visited 3 September 2014). Kleinman (1988).

¹⁰⁵ For Paul Farmer see <http://ghsm.hms.harvard.edu/people/faculty/paul-farmer> (visited 14 March 2014).

¹⁰⁶ Leon Eisenberg (d. 2009) was Professor of Psychiatry at Harvard Medical School, Massachusetts. For an obituary see http://www.nytimes.com/2009/09/24/health/research/24eisenberg.html?_r=0 (visited 14 March 2014).

¹⁰⁷ Professor Arthur Frank commented, '[Bully pulpit] is an American expression. It's a useful phrase. Being a Dean of Medicine is another example of a "bully pulpit", as shown by Dean's placement on various advisory bodies that don't require any medical expertise.' Email to Ms Emma Jones, 9 September 2014. The phrase is originally attributed to former US President Theodore Roosevelt, "The White House is a bully pulpit," said Theodore Roosevelt to George Putnam.' Quoted from Frost (1988), page xiii.

Hurwitz: Of course, he was drawing on an ethnographic tradition with its own methods.

Macnaughton: There's so much coming out there. Cecil Helman also, I think from this end, contributed to that kind of anthropological approach, being a physician himself.¹⁰⁸ I think he was very important – as somebody who came through my academic training in the late 1970s, 1980s, and then PhD into the early 1990s, the reading I did was not of that sort of theoretical material. In my PhD I used the word 'interpretation'; it was one of my key concepts but I never read these people. I read Schleiermacher, I remember, as one of my main people, I used on the notion of interpretation.¹⁰⁹ I'm recognizing now that people who are coming into the field in my centre who have this highly theoretical approach being driven, and I feel, I think personally, I sometimes feel very inadequate.¹¹⁰ I think I could have done with doing that kind of course, because I recognize in the kind of people that they are reading, particularly in the phenomenological tradition, which is another very strong one, and that's been a very important influence on us just now.¹¹¹ There's a big blank in terms of every time I look at this material I can see that it is a route to making sense, so exactly what you were saying, Rita.

Brockmeier: A word along the same lines – as you put it: there were all these great philosophers and, then, what happened in the 1980s? We have to probably put into the picture a number of middle men and even more middle women, who were important in the North American context: Hannah Arendt; Charles Taylor; Richard Rorty; and Donald Davidson.¹¹² Paul Ricoeur, who for many years taught in Chicago, also played an important role.¹¹³ In addition, there was also a generation of hermeneutically accomplished middle men and women in the social sciences, like Clifford Geertz and Jerome Bruner, whose

¹⁰⁸ Helman (1984).

¹⁰⁹ Friedrich Schleiermacher (1768–1834) was a philosopher who predominantly studied ethics. His work on hermeneutics was published posthumously; Schleiermacher (1998).

¹¹⁰ Centre for Medical Humanities, Durham University.

¹¹¹ Professor Jane Macnaughton was referring to, for example, the philosophers Heidegger, Husserl, Merleau-Ponty, and Sartre. Note on draft transcript, 4 July 2014.

¹¹² For Arendt, see note 55. See Taylor (1989); Rorty (1979); Davidson (2001).

¹¹³ See note 48.

Life as a Narrative was published in the 1980s.¹¹⁴ The 1980s began, and many people today think that Mitchell's *On Narrative*, published in 1981, counts as a good candidate for the narrative turn altogether.¹¹⁵ A few years after that, in the mid-1980s, Ricoeur's *Time and Narrative* came out, which was probably, philosophically, the most fundamental volume, actually three volumes, in those years.¹¹⁶ Many people, such as Paul Rabinow and Geertz, would have probably claimed that the overarching turn was the interpretive turn and in different disciplines at different times you had sort of little narrative turns, which were different in nature and structure in history and philosophy, and in the social sciences and anthropology than in medicine and psychology. If there is a period of time where we want to localize the emergence of narrative as a new multidisciplinary concept then it certainly is the 1980s.

Hurwitz: I think we've identified a series of strands and I suppose what we're trying to grapple with is how those strands are synthesized through action and theory into practices.

Frank: The other strand – I didn't know if you were going to invite this at some point – that needs to be brought in at this point is that especially in the United States you'd had some very high-profile memoirs of illness and the ill person was starting to speak and claiming the right to speak for him or herself. In the early 1970s Stewart Alsop, one of the most prominent political journalists in the United States, writing a regular column for *Newsweek*, developed leukaemia, and writing publicly about this;¹¹⁷ the journalist Betty Rollin *First, You Cry*, the breast cancer memoir; and the first lady, Betty Ford.¹¹⁸ All of a sudden you had all of these public tellings. Norman Cousins' *Anatomy of an Illness* was one of the few books I could immediately find when I was looking for things when

¹¹⁴ Professor Jens Brockmeier wrote: 'Both became influential figures in the "narrative turn" in the 1980s and 1990s.' Note on draft transcript, 4 November 2013. See Geertz (1973); Bruner (1987).

¹¹⁵ Mitchell (ed.) (1981). For more discussion of the 'narrative turn', see also, for example, Hyvärinen (2010), and Brockmeier (2013b).

¹¹⁶ Ricoeur (1984–1988; 1991).

¹¹⁷ Alsop (1973).

¹¹⁸ Rollin (1976). In 1974 the US First Lady Betty Ford publicly revealed she had a mastectomy as a treatment for breast cancer. Shortly after this announcement, Mrs Rockefeller, also a high profile public figure in the USA revealed she had breast cancer. On the subsequent media coverage of breast cancer in the USA see, for example, Corbett and Motomi (1999). For the UK response see, for example, Anon. (1974). See also Linehan (2006).

I had a heart attack in the mid-1980s.¹¹⁹ There was also Cornelius Ryan's *A Private Battle*, written from tapes he made privately, secretly, when he was dying of prostate cancer.¹²⁰ And then it continues: the poet Audre Lorde ...¹²¹

Hurwitz: This is a strand that's clearly not coming from the considerations of theory, of hermeneutics and interpretation.

Frank: It's not and that's why it deserves a very different mention because it has nothing to do with the traditions that Jens is talking about. It will hook up with what Anne and Kathryn were talking about because you begin to get high profile literary people, Reynolds Price's *A Whole New Life* being one of the most prominent, and Anatole Broyard's posthumous memoir.¹²² But if there's a line that deserves to go on the record, to me it's when Broyard says that his doctor 'is my patient also and I have my diagnosis of him'.¹²³ People who were ill began to read these accounts of either celebrity or intellectual, literary people writing in very direct, graphic ways about their illnesses. Susan Gubar's very recent book is about as graphic as you can get; it legitimated a form of talk, in going back to what Jane said of your medical student colleague, 'What do I say to the patient?'¹²⁴ All of a sudden there were all kinds of patients telling you what they wanted their physicians to say. I can't resist saying that my own memoir is still in print and had a kind of unique place in this, in that it was one of the few 'nobody memoirs' to be published by a major publisher, and to remain in print; unlike, really, all of the other memoirs that were by previously published authors or people who already had a public voice on something else.¹²⁵ So where did it come from? We could spend a very long time answering that.

Hurwitz: Yes. In your case, of course, it has more in common with these traditions than some of these other memoirs, doesn't it? I mean, in *At the Will of the Body*, you are drawing on a certain kind of narratological, sociological theory as well as your own experience.

¹¹⁹ Cousins (1979).

¹²⁰ Ryan and Morgan Ryan (1979).

¹²¹ Lorde (1980).

¹²² Price (1994); Broyard (1992).

¹²³ Broyard (1992), page 45.

¹²⁴ Gubar (2012).

¹²⁵ Frank (1991).

Frank: Well, we were all very eclectic in those days and we drew on what we had. We all just basically took what we had and part of what I had was Erving Goffman's work on stigma and asylums and that whole tradition of looking critically at medicine.¹²⁶ Another part of what I had was what I referred to earlier; it was going back to the civil rights movement becoming the Black Power movement. This crucial shift absolutely informed my thought that if patients are going to get something done, we can't wait for physicians to do it for us, that we need to step out of the patient role, we need to become ill people who are not patients, and we need to assert that we are examining our physicians. And then add disability. In the disability studies movement, Irving Zola did crucial work.¹²⁷ He was another kind of friend, quasi-mentor to me. All of this, and disability rights, would not have been possible without the other rights movements that came first, politically. It was one of those moments when you've got all the intellectual movements that Jens and others have been referring to, that then tie into something that just happened. Why, in the 1970s, did widely recognized people, such as Stewart Alsop of *Newsweek*, start writing about their cancer?¹²⁸ It was definitely the 'informing a public' mood that then created a constituency, so that the work that Rita and others were doing was immediately recognizable as meeting a demand that was out there.

Dr Catherine Belling: I'm wondering whether there isn't a clearer connection between what Art is talking about and the narrative turn in virtually all the textual humanities fields or intellectual or social science fields, because of the 1970s and 1968 and the rise of rebellion in so many different forms.¹²⁹ I wonder if that doesn't come back to medical ethics and the fact that medical ethics is developing at the same time. When you introduced informed consent, which was 1972 in the United States, patients get to decide what's going on and then patients' stories become a valid kind of account.¹³⁰ I think that idea that, again, with Hayden White's idea about history also destabilizing the completely

¹²⁶ Goffman (1961).

¹²⁷ Zola (1982).

¹²⁸ See note 117.

¹²⁹ For 'narrative turn' see notes 114 and 115.

¹³⁰ The year 1972 relates to three landmark legal cases in the USA in which issues of informed consent went on trial from professional and patient perspectives, and the year of the American Hospital Association's adoption of 'A Patient's Bill of Rights'; see Faden and Beauchamp (1986), pages 93–5 (Patient's Bill of Rights) and 132–8 (landmark cases).



Figure 12: Dr Catherine Belling

authoritarian version of ‘this is what happened and these are the dates’ to the more specific, ‘this is one way of telling, here is the particular rather than the reductivist idea’, that this is, you know, the authorized history, again ties in with the idea that the individual’s voice speaking from below in the hierarchy is, I think those are coherent with each other.¹³¹ But there are real connections to be found there.

Professor Jeff Aronson: I have collected a bibliography of about 350 or 400 titles of ‘patients’ tales’, by which I mean book-length accounts, not articles; there must be as many again, or maybe more, of the latter. I prefer to call them ‘patients’ tales’ or, if you like, ‘Plain Tales from the Ill’, to paraphrase Kipling.¹³² But I guess the technical term would be autopathography and the first time that term was used was 1991, as far as I can find, in modern times at any rate,

¹³¹ Professor Kathryn Montgomery wrote: ‘The narrative turn in bioethics, which had its tentative start with the fifth volume of *Literature and Medicine* that Anne mentioned, culminates for me in Tod Chambers’ *The Fiction of Bioethics*, which considers philosophers’ cases not as coolly objective thought experiments but as narratives constructed rhetorically to enforce their makers’ point.’ Note on draft transcript, 3 November 2013. See Chambers (1999), and note 32. For Hayden White, see note 103.

¹³² Kipling (1889).



Figure 13: Professor Jeff Aronson

by Thomas Couser.¹³³ When I wrote a paper on this called ‘Autopathography: the patient’s tale’, I thought I’d invented the term but in fact I then discovered that others before me had used it and in each case everybody seems to think that they invented the term.¹³⁴ Couser uses it, as far as I can discover, for the first time in 1991 but it had already been used by a man called Clarence Farrar in 1911 in a paper published in *The American Journal of Insanity*.¹³⁵ But I don’t think anybody had actually recognized it as a genre until the 1980s or 1990s. Now if you look at the distribution through time of all these accounts, the earliest is in the first century AD by a man called Aelius Aristides in Greek, and it’s an account of his hypochondria and his relationship with Apollo as his physician.¹³⁶ And then there are sparse accounts thereafter; one thinks of books by de Quincey and many others.¹³⁷ But suddenly in 1980, there is this huge burgeoning of accounts, patients’ tales in book form, and no doubt at the same time journal articles; and there may be many influences, as you have discussed.

¹³³ Couser (1991).

¹³⁴ Aronson (2000).

¹³⁵ Farrar (1911).

¹³⁶ See, for example, King (2014).

¹³⁷ de Quincey (1822).

One may be what people call medical secularization, the medical confessional in a secular time replacing confessions of one sort or another. Another influence I think that might be worth mentioning is Susan Sontag's influential extended essay on tuberculosis and cancer, later further extended to include AIDS, which was published in 1978, which I think may have had a huge influence on the way people's attitudes changed to narrative and patients talking about themselves but which may really have reflected the zeitgeist rather than being itself influential.¹³⁸ It would be interesting to know what others think.

Launer: I'd love to introduce another thread at this point, which is the narrative turn in the psychological therapies. My own background is as a family therapist, as well as a family physician, and I was initially trained entirely in metaphors coming from cybernetics and people like von Bertalanffy.¹³⁹ And metaphors coming from biological systems; people like Bateson and Maturana.¹⁴⁰ Towards the end of the 1980s there was a quite radical turn towards linguistics, with Harold Goolishian and Harlene Anderson at the Houston Galveston Institute talking about human systems as linguistic systems.¹⁴¹ There was a very, very swift move towards a linguistic turn rapidly followed by a narrative turn so that by the end of the 1990s people like Michael White and David Epston were explicitly talking about narrative therapy.¹⁴² Now, in a way you can trace this right back if you look at the Milan Team and other very influential people in family therapy.¹⁴³ They were talking about language much earlier but certainly by the early 1990s people were talking about therapy through language, and by the end of the 1990s they were talking about therapy through stories and re-storying.¹⁴⁴ And it happened very, very quickly and I think it then started to percolate into medicine, back from medicine, all sorts of directions. There was a real interfusion from all these different fields.

¹³⁸ Sontag (1978).

¹³⁹ Karl Ludwig von Bertalanffy (1901–1972) is associated with the philosophy of 'general system theory'; <http://www.bcass.org/bertalanffy/> (visited 6 May 2014). See von Bertalanffy (1968).

¹⁴⁰ See Bateson (1972); Maturana and Varela (1987).

¹⁴¹ See Anderson and Goolishian (1988).

¹⁴² White and Epston (1990). For narrative turn, see also notes 114 and 115.

¹⁴³ For the Milan Team's publications, see, for example, Selvini *et al.* (1980), and Cecchin (1987).

¹⁴⁴ For the influence of the Milan Team on narrative approaches to medicine, see Campbell (2003). For re-storying, see White (1995).

Montgomery: I just want to add Ernst Gombrich to the whole mix. He would deny that he was hermeneutic, in fact he did quite vehemently; he claimed to be uninfluenced by the French and the Germans and all those deconstructionists, but his work in the interpretation of art and the construction of meaning from postage stamps and other amusing things he did, is very much in the hermeneutic tradition.¹⁴⁵ And actually now that I think of it, it was a big influence on me because before I turned to trying to make sense of my clinical colleagues' discourse, I studied satire.

Hurwitz: What happens after 2000? Has a coherent disciplinary edifice been built? A number of people have indicated that it would be a great shame if we leapfrogged over the question of how an evolving narratological consciousness in health interacted with medical ethics in the 1980s/1990s. What happens when the sufferers' accounts come up against medical ethicists' case formulations, moral principles, and values?

Frank: There are a number of ways of telling the story, so I will propose what I think is a defensible, but highly contestable, version and then others can say, 'No, no, no, that wasn't what happened, this is what happened'. My defensible version is that you began in the 1960s with a prophetic stage: Jay Katz's *The Silent World of Doctor and Patient*; Paul Ramsey's *The Patient as Person*; Joseph Fletcher's work.¹⁴⁶ These people were all genuinely prophetic in that they were saying, 'Look, there's something horribly wrong here'. Their work gained a public profile because of scandals like Tuskegee, Willowbrook,¹⁴⁷ words that have become code words now in referring to ethical problems in medicine. But then very quickly turned with the formation of the Hastings Center and then a little bit later the Georgetown Center into a professional stage,¹⁴⁸ and when someone quoted Dan Clouser saying earlier, 'Physicians are doing things and they don't have a principle for doing that',¹⁴⁹ I hear that as the professional stage. I think when those institutes started they had two major concerns: one was to legitimate the presence of the professional bioethicist in the hospital wards, so that you would

¹⁴⁵ Gombrich (1963), pages 56–69.

¹⁴⁶ Katz (1984); Ramsey (1970). See, for example, Fletcher (1966).

¹⁴⁷ See, for example, Rothman (1982); Jones (1981); Krugman (1986).

¹⁴⁸ The Hastings Center (New York) was originally known as the Institute of Society, Ethics, and Life Sciences. For Georgetown, see Reich (1994), note 12 and the Center for Clinical Bioethics' website; <https://clinicalbioethics.georgetown.edu/about> (visited 8 May 2014).

¹⁴⁹ See Professor Kathryn Montgomery's comments, page 18.

move from the lay ethics committee to having a professional bioethicist. And the committees had come in, again depending on whose version of the story you tell, in response to problems like the allocation of kidneys – as soon as you had the allocation of dialysis machines early on.¹⁵⁰ Originally they were often called ethics and prognostication committees because what would appear over and over again before the committee was termination, whether it was legitimate to remove life support that had been started. So you had practical problems in medicine, and here I'll be a little sceptical; they wanted to do the right thing, of course, they also wanted liability control. They also wanted a certified expert who could tell them that this was the right thing that they could take to court later on and say: 'We asked an expert and this was a properly considered judgement.'

The early people were concerned with having professional bioethicists who could take authoritative positions. They were also concerned with what the Hastings Center still has, which is financial dependence on research investigation grants. You had to have a profession that would open up a regular grants' stream from various funding bodies, and if we leave out the institutional aspects of all this, we're only telling half the story. It's not all about ideas, it's also about jobs, positions, money changing hands, and so on. So you moved into a professional thing and everybody started doing principles, because if you're going to be a certified professional you've got to have, basically, a product that you're putting out there and they had principles that provided decision-making algorithms. Now here we get to what's the really interesting part to me because as soon as you'd got those, the principles solidifying into Beauchamp and Childress' so-called 'Georgetown mantra', you got what really matters, which is a reaction against them.¹⁵¹ And so you then began to get an anti-principle literature, which is where I started doing bioethics in the early 1990s.¹⁵² I'm very glad to have come in right then because, again, that, to me, is where it gets fun because academic life works best when you've got some establishment centre and then everybody else can sit on the outside and take shots at it. Then you got a narrative ethics

¹⁵⁰ On decisions about kidney patients who would receive dialysis in the USA, in the 1960s, and specifically in Seattle and the subsequent emergence of bioethics see, for example, Jonsen (1993) and Alexander (1962). For a discussion of the politics of kidney patients' 'selection' for dialysis treatment in the UK and USA, see Crowther, Reynolds and Tansey (eds) (2009); pages xx–xxi, 69–72.

¹⁵¹ For the 'Georgetown mantra', defined as four moral principles for biomedical ethics: respect for autonomy, nonmaleficence, beneficence and justice, see Beauchamp and Childress (2009), pages 12–13, and chapters 4–7, pages 99–280. For a critique of the four principles approach, see Takala (2001).

¹⁵² For a history of bioethics see, for example, Pellegrino (1999), and Fox, Swazey, and Watkins (2008).

group, phenomenological ethics groups, a feminist ethics group, you got all of these basically anti-principlist groups forming. The last part I'll mention is this whole issue of what happened to the voice of the patient in all of this. In the principlist version, the voice of the patient is almost a contingency and a lot of the principlist emphasis came out of a strong analytic philosophy tradition. I remember one colleague writing about some other colleagues indulging themselves at the bedside.¹⁵³ There were some ethicists who made it a matter of professional pride that they did not go into the room because that would be to confuse the decision with emotion and if the decision was to be made on a properly principled basis, you didn't want to get emotionally involved with the patient and the family. So this was emphatically not ethics, bringing out what you called the voice of suffering earlier. Informed consent, as I understand it, was emphatically not about patients' voices.¹⁵⁴ It was reducing the patient's voice to a 'yes I do' or 'no I don't' binary acceptance/rejection, not: 'Tell us the story of how you feel about this.' It was: 'Do you or do you not consent to it?' I see it as a shutting down of narrative, much more than an opening up of narrative as it was institutionalized, and it's crucial here to separate how it was institutionalized from the motivation of the prophetic group that was calling for it much earlier.

What you've got now is absolutely all over the board. The name that needs to be brought in here, to be honoured, is Richard Zaner.¹⁵⁵ If you're looking for narrative in bioethics, the service that Dick Zaner started at Vanderbilt (University School of Medicine), after already having had a very successful career as a phenomenological philosopher, student of Alfred Schutz and Aron Gurwitsch, leaving academic philosophy, starting this, not taking a vacation for ten years because he realised he had to be on call, and just living an incredibly dedicated life. Dick's book *Troubled Voices*, which as a 'troubled' publication is hard to get hold of, his book *Conversations on the Edge*, which was published by Georgetown, is much easier to get hold of and there are also various journal articles and a special issue of *Human Studies* that he and his students did.¹⁵⁶ That consultation service now has been taken over by Larry Churchill, who regretted

¹⁵³ See Tomlinson (1999).

¹⁵⁴ See note 130, and also, for general discussions of the history of informed consent's evolution post-Nuremberg Trials, see Faden and Beauchamp (1986), pages 125–87.

¹⁵⁵ For further details on Richard Zaner's influence in the field of narrative and bioethics, see *Theoretical Medicine and Bioethics* (2005). See also Zaner (1993, 2004).

¹⁵⁶ Zaner (ed.) (1999).

not being here today.¹⁵⁷ Larry could talk about how he's perpetuated that work, but Larry's book *Healers* and his forthcoming book *What Patients Teach* is where you find the voice of the patient, the ill person who is suffering.¹⁵⁸ But it's still a radical move, and Larry is now proposing a reorientation of bioethics so that it becomes centred on these questions of suffering. This will be a shift, for bioethics to go in that direction.

Aronson: Just to comment on how teaching of medical students in ethics came about in the UK. I think that it started in a major way in the 1990s when the General Medical Council (GMC) published the first version of its report entitled *Tomorrow's Doctors*.¹⁵⁹ This is a document that outlines what the GMC expects newly qualified doctors to know and be able to do. The latest version, 2012, has radically changed in many ways from the first version, but in the early 1990s the feeling was that there was far too much factual knowledge for medical students to learn and that some of it ought to be replaced by practical skills, and practical skills included ethics. And that's how the institute Ethox started in Oxford, and others like it doubtless elsewhere.¹⁶⁰ So I think in the 1990s there was a huge increase in the amount of ethics teaching that medical students received because of that perception that there was just too much to learn factually, that it would be much easier for the students to be trained in ethical principles.

Hurwitz: One slight qualification here is that in the UK the first major report about the teaching of medical ethics is the Pond report, in the 1980s, and it reflected a debate then about the value of medical ethics being philosophically driven – philosophical medical ethics was the term used to distinguish it from code-based ethics.¹⁶¹ In an appendix arguing the importance of philosophy, moral theology, and law to medical ethics, the distinguished philosopher Jonathan Glover confessed that were he to be given a choice between placing

¹⁵⁷ See biography on pages 80–1.

¹⁵⁸ Schenck and Churchill (2012); Churchill, Fanning and Schenck (2013).

¹⁵⁹ General Medical Council, Education Committee (1993). The 2009 edition of this publication can be freely downloaded from the General Medical Council's website: http://www.gmc-uk.org/Tomorrow_s_Doctors_0414.pdf_48905759.pdf (visited 8 May 2014). See also, General Medical Council (2009).

¹⁶⁰ The Ethox Centre for bioethics is part of the University of Oxford's Nuffield Department of Population Health; <http://www.ethox.org.uk/> (visited 8 May 2014).

¹⁶¹ Boyd (ed.) (1987). For comments on the Pond report's significance and its origins, see Reynolds and Tansey (eds) (2007), pages xxii–xxiv and 58–62.

life and death decisions about himself – medical or non-medical – in the hands of a group of doctors or philosophers he would ‘without hesitation choose the doctors’ on the grounds that ‘good doctors develop a sensitivity to human consequences of different courses of action, an intuitive feel for the relative weight of different factors...’, though they may not articulate this well. ‘Good philosophers’, he continued, ‘reason well but often do not have much feel for the human aspects of these decisions. In philosophy reputations are gained for cleverness and ingenuity rather than for humanity.’¹⁶²

Aronson: At the same time, of course, what you would call in the USA Institutional Review Boards – I suppose, ethics committees, research ethics committees in the UK – were beginning to develop and burgeon in the 1980s and in fact I was Chairman of the Central Oxford Research Ethics Committee at that time and watched the whole process of ethics in research develop at the same time as ethics teaching was beginning to take place in the schools.¹⁶³

Hurwitz: And in research ethics committee proceedings, the suffering voice of the patient had a low profile. Does anybody want to comment on the voice of the patient in Institutional Review Boards or local ethics committees?

Aronson: What I can remember is that the main concern of the ethics committee was almost always to do with the piece of paper that was supposed to give patients information about the study and on which they were asked to give their consent. The rest, the way in which the study was designed, all the details about the actual procedures, was pretty much left to the side in favour of a close scrutiny of that ‘sheet of information’ paper. So there was an increasing awareness of the importance of informing the patient, but whether the patient’s voice was being heard is another matter.

Charon: I hope, and I think, that we’re still at a very primitive stage of what eventually will be thought of as the ethics of care. It really was, in the States anyway, it was a really shady competition between the philosophers and the others in the humanities interested in issues of suffering and death and dying. And as we think back on it, was it Clouser or Stephen Toulmin who said that ‘bioethics is a way for philosophers to get jobs’? So bioethics kept alive the philosophers, he had a line.

¹⁶² Quoted from Boyd (ed.) (1987), pages 54–5.

¹⁶³ For Institutional Review Boards, see Maloney (1984), pages 47–115. For the formation of research ethics committees in the UK, see Alberti (1995).

Hurwitz: It was Toulmin. The line is: ‘How medicine saved the life of ethics.’¹⁶⁴

Charon: But it had to do, I think, thinking back from now, like who had the province? Which intellectual discipline had the province, to be adjudicating, to be governing, to be conceptualizing the moral issues at stake in illness? And, if you even look at the professional societies in the States, we started with this very democratic, loose affiliation in the Society for Health and Human Values and it was philosophers, historians, religious studies, chaplains, doctors, nurses, social workers, dentists, and the whole group of us from literature.¹⁶⁵ And it was very kind of egalitarian and then some ten years into that arose another society, which was the Society for Bioethics Consultation (SBC); that was an effort to fulfil the mandate now overseen by the Joint Commission on Accreditation of Hospitals, which is the organizing board of hospitals, that each hospital needed to have an ethics committee.¹⁶⁶ So there arose the SBC to govern and be the professional group for those who did the ethics consultations, which of course got paid for by the hospital because they were required to by JCAH – the group that covers hospital doings. And then there became a long, complex, and still very vexed effort to bring these together into the American Society of Bioethics and Humanities (ASBH), which is what maintains now but it’s still overwhelmingly presided over by the ethicists, most of them from philosophy.¹⁶⁷ And Catherine Belling and I, and others here, have been on various committees. I think Catherine was the Programme Chair one year, but there’s still this great resentment from the non-ethics humanities persons, not only literature but the feminist groups and certainly the disability scholars, for some kind of leadership and control of this group. I’ll stop there but I think as I look back it was this kind of nasty, internecine struggle among the disciplines.

Hudson Jones: There was a third group too, the AAB, the American Association for Bioethics, and these were primarily the academic philosophers, so there were a lot of reasons I think for some of that, but it was the three of these very disparate groups trying to come together into the ASBH.

¹⁶⁴ Toulmin (1982).

¹⁶⁵ See note 98.

¹⁶⁶ For the Society of Bioethics Consultation, see note 98. The acronym was JCAH when the Commission was created in 1951, then JCAHO in 1996 when a website was launched, www.jcaho.org. The organization is now entitled the Joint Commission; for a history see http://www.jointcommission.org/about_us/history.aspx (visited 14 May 2014).

¹⁶⁷ For further details, see the American Society of Bioethics and Humanities website; <http://www.asbh.org/about/content/purpose-of-asbh.html> (visited 15 May 2014).

Macnaughton: Yes, I really recognize that because we, for the first time – when the ASBH conference was in San Diego in 2010 – three of us from my centre went to visit the conference with the purpose to hook up with the people working in the field of medical humanities, and we found not a lot there for us to engage with, really not a lot actually. So we haven't been back. But it demonstrates a big divergence between what's happening in the UK and what's happening in the States, because our Association for Medical Humanities has nothing to do with ethics at all. It's really very much humanities-based, has an arts and health element to it, and I've just been talking to Catherine (Belling) about the fact that this year the theme is global medical humanities, so it has gone much more research-orientated.¹⁶⁸ So it's an interesting thing to reflect on, that divergence of the States and the UK. I think in Continental Europe the Scandinavians are probably much more like the UK, or we are much more like them in terms of the ways in which the field is now developing actually.

Hurwitz: One thing worth mentioning is that the journal *Medical Humanities* in the UK, initially was a twice-yearly edition of the *Journal of Medical Ethics* and so it had, in a sense, to distinguish itself from its parent journal. I want to move the discussion forwards, to thinking about the last ten years. A question I'd like to ask is whether the composite of narrative studies in medicine has been accepted as a field that has its own contributory research and pedagogical values, methods, and roles to play in medical and nursing practice? We heard about a profusion of different thematics and strands of activity. One question: is a synthesis possible? Are we moving towards some kind of assimilation of narrative thinking and teaching into mainstream healthcare? Or do they remain peripheral and, in some sense, in tension with mainstream healthcare practices?

Macnaughton: Earlier on the GMC document of 1993 was mentioned and I think it's important to add, about the ethics, that that document, for the first time, allowed for humanities-based modules to be taught as an assessed part of the undergraduate medical curriculum.¹⁶⁹ That gave a huge boost to the kind of educational work we were doing within curricula and was extremely important and I think that led to the development of quite a number of centres that delivered that kind of work. My impression now is that we're actually going backwards in terms of that. They're now called 'student selected components',

¹⁶⁸ The Association for Medical Humanities (UK) was founded in 2002 at a meeting held at the University of Birmingham; see <http://www.amh.ac.uk/about> (visited 15 May 2014).

¹⁶⁹ See Professor Aronson's comments on page 71.

and do not have that same sense of the GMC 1993 document in that it was these modules that would allow you to take advantage of the opportunities available at your university, so if you have a university that's really very top-notch in history or English studies or whatever, you could take advantage of that. But that doesn't seem to now be the flavour of those modules, which is a sad thing. I said this rather challenging thing about education and research,¹⁷⁰ and it has struck me that what we have done in the education field, and I ran a number of these modules myself, I did get increasingly frustrated about the fact that we were continually preaching to the converted, we weren't really able to get at that group of students who maybe really did need to hear the kinds of messages that we were trying to portray because this was always only a minority.

I think in a number of universities, through the GMC's changes, we were able to start to introduce this through some of the early patient contact work, so we had things like personal professional development courses but again so much of that, as has already been mentioned, was based on a kind of skills training. So what kind of skills can your modules offer rather than a sense of changing attitudes or bringing a larger perspective to bear? And that again was challenging. So I've felt, in my approach to this field, very much continually defeated by that undergraduate medicine approach and a sense certainly over the last few years that engaging with people who are in practice, who are now in practice, who are coming back and saying, 'Actually there's a heck of a lot that we need support for in our practice', particularly GPs with whom I've been engaging much more recently. But at the same time, for what we're now beginning to call critical research-based humanities, the idea of that is actually, if we were putting our money where our mouth is and saying, 'well, if we do want to change the culture of medicine, where we need to work is to get at how the evidence base gets generated.' So what we need to say is, 'well if we really do believe that the kind of narrative approach or that stories matter, or that all the mysterious aspects of human experience, phenomenological experience, matter in terms of illness experience and that actually affect the physiology', then we need to be right alongside these kind of scientists bringing our perspective to bear on discussions about how experiments are carried out, about the kinds of questions we ask patients who are in a brain scanner about their neurological experience, and how these are replicated. So to my mind, I think the field, certainly in the UK, in terms of the funded centres for medical humanities that are now developing, this is the flavour that they are taking on.

¹⁷⁰ See page 31.

Brockmeier: Well, I would like to distinguish some different aspects or levels of an answer to your question: ‘What about a synthesis?’ Can we cohere all these stories to one big narrative of narrative medicine? I think there are different questions concerning bioethics, the medical humanities and narrative medicine or narrative-based medicine, and research on narrative and medicine. I want to say something only about the last of these aspects or levels. I think it’s going to be difficult to imagine a synthesis. We have been talking here mainly about these issues from a medical point of view, perhaps adding some views from the social sciences. What we have not considered is that, at the same time, while these developments towards a narrative medicine have taken place, there have been interesting developments on the narrative side, within the narrative fields, or, more precisely, within the study of narrative and the narrative-based study of human matters. We should not forget that the narrative turn was not only an event, or events, in a number of different disciplines but it also took place within narrative theory, or narratology, or narrative studies.¹⁷¹ Today, narrative scholars within the humanities have quite different views of what narrative and storytelling is all about than, say, 40 or 50 years ago. Let me mention just a few important things that have changed. First, the basic orientation of narratology has changed by what has become known as the turn from classical to post-classical narrative theory. What has dissolved with this turn is the idea that there is a well-defined story, a clear-cut definition of what narrative is, and what it is not, a basic vocabulary that can give coherence and structure to narrative analysis. Previous, classical ideas of structure and narrative coherence were all strongly influenced by the structuralist conception of narrative that dominated discussions in the middle decades of the last century.¹⁷² The turn to post-classical narrative has challenged the assumption that narrative is a concept correlated with literature and literary texts in the first place. All great narratologists shared this assumption. Second, it challenged the assumption that narrative has to do with texts in the first place, opening up paths to all kinds of non-literary and non-text-based forms and practices of narrative discourse, for instance in

¹⁷¹ See page 46.

¹⁷² See, for example, Lévi-Strauss (1955) and Barthes (1966). Professor Brian Hurwitz commented that the Lévi-Strauss citation was a ‘hugely influential paper which in part initiated the idea of myth as permutations of storied elements – structured almost as crystals but with slight variants or declensions. This in turn led to narratives themselves being subject to analysis as structured variants’. He further wrote, on the cited Barthes chapter: ‘This is probably the most important piece of work Barthes published at this time on the importance of narrative. It’s been translated and quoted thousands of times.’ Notes on draft transcript, 15 July 2014.

everyday contexts of face-to-face interactions.¹⁷³ In this way, third, it has also challenged the distinction between fictional and non-fictional discourses, which for a long time was an important distinction. Fourth, it has even challenged the idea that narrative is primarily a linguistic enterprise, rather than a form and practice that can be enacted in visual and performative ways in different semiotic environments, not least in digital media platforms.¹⁷⁴ Related to this are interesting developments going on in body-based or corporeal narrative theories of embodied narrative.¹⁷⁵ Narrative, in this view, appears less as a form of text or discourse, as in the classical days, and more as a ‘form of life’, as we might say using Wittgenstein’s terms.¹⁷⁶

Dr Craig Irvine: We are very much still in our infancy in this narrative medicine movement and I don’t think there is enough historical perspective yet to really say exactly how all of this is really going to cohere. I think that’s what makes it a particularly exciting time and an apt time for this meeting to happen. We’re having our first international conference on narrative medicine this week and the voices that are going to be represented there are extremely diverse.¹⁷⁷ And how this all comes together, what it means for it all to be under the same umbrella, I don’t think we quite know yet. So I fully support that point that I don’t know that there will be one cohering vision but there certainly is a strong tide, if one can feel a sense of purpose, a united purpose and yet not feel as if

¹⁷³ Professor Jens Brockmeier wrote, ‘This has allowed us to bridge the gap between sociolinguists, conversation and discourse theorists, and traditional narrative theory which was literature-oriented.’ Note on draft transcript, 4 November 2013.

¹⁷⁴ See, for example, Barthes (1977).

¹⁷⁵ Andrews, Squire and Taboukou (eds) (2013).

¹⁷⁶ Ludwig Wittgenstein (1889–1951) is widely considered to be one of the most important philosophers of the twentieth century. The ‘form of life concept’ appeared in his later writings, *Philosophical Investigations*, first published posthumously in 1953; see Wittgenstein (2009).

¹⁷⁷ See note 1. Professor Brian Hurwitz wrote, ‘It’s actually the *third* I know of: [1] ‘Narrative Based Medicine: an Interdisciplinary Conference – Research, Teaching and Practice’ – a two-day International Meeting, Homerton College, Cambridge UK. BMJ Conferences Sept 2001. Organisers: Brian Hurwitz, Vieda Skultans and Trish Greenhalgh; [2] ‘Narrative Research in Health and Illness, a two-day International Meeting’, School of Oriental and African Studies, BMJ Conferences, Sept 2004. Organisers: Brian Hurwitz, Trish Greenhalgh and Vieda Skultans.’ Email to Emma Jones, 28 September 2014. See also further correspondence from Professor Brian Hurwitz, Dr Craig Irvine, and Professor Rita Charon concerning their different perspectives on international conferences relating to the topics of this meeting in the archives of this Witness Seminar, available at the Wellcome Library, London: Archives and Manuscripts GC/253.



Figure 14: Dr Craig Irvine, Professor Maura Spiegel, Professor Jens Brockmeier

we're all under one controlling idea. I think that gets us toward where we want to think of ourselves at this point. I think it's very good and productive that we don't have one cohering vision, one field that speaks with one voice for all of this work. And what's been incredibly exciting for us at Columbia University is bringing together all of the faculty from various fields and we continue after decades of working together to teach each other from our fields and to learn again and again what we have to offer each other.

Launer: Another response to your question, Brian,¹⁷⁸ I think it's consistent with what Jens and Craig have both said, I think there are an awful lot of ships sailing around the ocean with narrative written on the side, a bit like Liberia. And you know Liberian ships haven't necessarily ever been any closer to Liberia.¹⁷⁹ But at the same time I think there are two ports, if I can extend the metaphor, that they always call in at and I think one port has got something to do with narrative being a counterbalance to evidence-based medicine and

¹⁷⁸ See page 53.

¹⁷⁹ The Liberia reference is to the 'flags of convenience' practice of ship registration in which owners register their vessels with countries other than the major maritime states to avoid stringent safety inspections or the monitoring of environmental regulations, among other issues. Liberia is a key provider of such 'flags'. See, for example, DeSombre (2006), pages 71–4.

that really for me was the major theme of the book that you and Trish edited in the late 1990s.¹⁸⁰ The other port that they call in at actually relates to the book that Rita wrote, which is about narrative competence.¹⁸¹ I think those two ports counterbalance with evidence-based medicine, and narrative competence is what holds all this fleet together. And for me, personally, the power of narrative has been its use as metaphor in the context of teaching interactional skills, communication skills, which is another theme that's been implicit in a lot of what has been described but not actually named. But it provides a set of metaphors that one can use to teach skills for the patient encounter, teach skills for peer supervision, and it's a very compelling metaphor that everybody can relate to in a way that they can't necessarily relate to the metaphor of patient-centred medicine or other systems.¹⁸² I've rarely, if ever, met anybody who couldn't think of their skills for the consultation or their skills for supervision in terms of listening to a story, of questioning a story in such a way that a different form of the narrative emerged.

Hurwitz: So that places this kind of competence in a very interpersonal and intersubjective space.

Aronson: Can I say, I don't see narrative as a counter to evidence based medicine, I see it as being complementary, and I feel that narratives can contribute evidence, sometimes very strongly. Anecdote is not just the singular of data. A good anecdote, a counter example, can be very powerful evidence. I was at a conference last week on observational studies and the use of observational data, and I suggested that we should be using all kinds of evidence from randomized trials, systematic reviews, observational data, and narrative reports of one sort or another, to construct evidence about all kinds of things in medicine.

While I have the microphone can I say something about teaching? We've mentioned the GMC and its *Tomorrow's Doctors* report.¹⁸³ That report did quite a lot of harm to some medical teaching. It, for example, did not mention, or hardly mentioned, prescribing and therapeutics and in the following two decades the subject of clinical pharmacology, which is my subject, declined markedly,

¹⁸⁰ Greenhalgh and Hurwitz (eds) (1998). See note 209.

¹⁸¹ Charon (2006).

¹⁸² For further discussion of these topics, see Launer (2002), and also Sommers and Launer (eds) (2013).

¹⁸³ See note 159.

as we've heard in a previous Witness Seminar.¹⁸⁴ And only in the last few years has it been reviving, with the realization that everybody, all doctors and others, prescribe and that prescribing is important. Now this raises the question of what you teach in the core curriculum: what are the basic, important things that all medical students should learn? And it would be interesting to explore the question of what facets of narrative need to be taught to medical students as a part of their core studies – whether there are certain aspects of it, be it ethics or narratology, or whatever, that are absolutely essential and what facets of it can be left to the voluntary parts of medical education, such as the special study modules that were referred to before.¹⁸⁵

Launer: Just a response, very briefly, to the first part of what Jeff said, which I completely agree with, and I often quote Rita as saying, 'I think that all evidence is a form of narrative and all narrative is evidentiary'.¹⁸⁶ I think one needs to talk of counterbalancing rather than countering each other.

Frank: I also want to elaborate on what you've put very well because I think you're steering us in the direction this conversation needs to go, to address the present decade and what's happening. My sense of the fundamental tension is that, and here I'll be jargonistic, neo-liberal medicine, as Howard Brody writes in his recent work, fundamentally works on a basis of what he calls 'economism', according to which 'economic calculation is the best way to understand, value, and manage every aspect of human life'; the tension between medicine as delivering a technical service, treatment in a restricted sense, and medicine as the expansive care for suffering.¹⁸⁷ Here, I wish Eric Cassell had been able to accept your invitation because it's Eric who has really made that the core theme of his life work.¹⁸⁸

¹⁸⁴ Two previous Witness Seminars addressed the history of clinical pharmacology in the UK: Reynolds and Tansey (eds) (2008a, b).

¹⁸⁵ See pages 53–4.

¹⁸⁶ The precise quotation relates to the Narrative Evidence-Based Medicine (NEBM) project at Columbia University: '... our project recognises the narrative features of *all* data and the evidentiary status of *all* clinical text', quoted from Charon and Wyer (2008).

¹⁸⁷ Professor Arthur Frank further commented, 'Brody contrasts that way of thinking with ideals of care that bioethics is based on.' Note on draft transcript, 10 July 2014. See Brody (2013), quotation on page 180. See also Brody (2011b), and the author's blog: <http://brodyhooked.blogspot.co.uk/2011/11/shameless-commerce-division-new-book.html> (visited 14 July 2014). See also page 31, and note 82.

¹⁸⁸ Eric Cassell is Emeritus Professor of Public Health, Weill Medical College, Cornell University, New York. See <http://ericcassell.com/bio.html> (visited 15 May 2014). See, for example, Cassell (1985).

I think this is the present crisis, and whether we're talking about reimbursement of practice and organization of conditions of practice, whether we're talking about length of visits, whether we're talking about accreditation, whether we're talking about curriculum units, priorities in curriculum, to me the 'soul of medicine' issue in all of this, is whether there will be sufficient voices to maintain the mandate of care. When I read Rita's work, I read the clinician as a moral witness to the primacy of the caring relationship between yourself as a person and your patient as a person, and the meeting of these two faces in Lévinas' sense of ethics.¹⁸⁹ That's where ethics is no longer bioethics, it is now the ethics of the confrontation of the suffering other. This, to me, is where the heaviest stakes for narrative medicine are right now. Narrative medicine, I think, is speaking for the mandate of care as something that is far more expansive than the mandate of treatment and, really, all the physicians in this room represent part of that and, for me coming at this from the patient side, the great pleasure of the last 20 years has been finding more and more allies in medicine, who wanted to be the kind of physicians who I originally began to write about from the ill person perspective saying: 'This is what we need. When we are ill we need this kind of physician.' Then I find people like Rita and John, and others, who want to be those kinds of doctors. That's the tension to me, and I want to underscore it's a political–economic tension.

Charon: In our work at Columbia in narrative medicine I think we're very, very faithful to the primacy of the mandate to improve healthcare, and that's why we're doing this, it's not to extend our own theoretical literary, narratological, or philosophical expertise but we're there to improve the healthcare.¹⁹⁰ At Columbia it's required of all students, in all four years, and now it's extending into the Nursing School, Dental School, and the School of Public Health. But it's required, it is not for the chosen few. It is a maturation of the institutional culture and I'm not going to make any claims about the means by which these practices, these habits of narratively skilled care of the sick we've been watching, how these are slowly saturating the institution. The medical students now at Columbia are required to keep an archive of the writing they do through the whole year. Both Craig and Maura teach required courses for our medical students. Maura teaches in cinema studies, Craig a

¹⁸⁹ See, for example, Lévinas (1998). For elucidation on Frank's thoughts on Lévinas' ethics, see also Frank (2004), pages 48–52.

¹⁹⁰ For further details about the Program in Narrative Medicine at Columbia University Medical Center, see <http://www.narrativemedicine.org/> (visited 15 May 2014).

seminar in the philosophy of death that our students take in order to fulfil a requirement for their graduation. But I just want to put onto our table this gradual saturating, institution-wide set of habits, that's by no means reached all of the practitioners and it certainly hasn't reached to the level of who gets paid for what, but yet there is beginning to be an ethos among how the students are taught to practise, how the students are given, not just the invitation but the requirement to do creative work as they're becoming physicians. Our colleague Nellie Herman is a novelist, a fiction writer, and she has been very, very clear with us that creativity is the most important ingredient in how we are to improve healthcare.

Irvine: Just to reinforce a point that Arthur was making: I think that, in fact, what we're seeing both in those individuals who come to our workshops and the people that are coming to our Master's programme, is that much of the interest is driven by the tensions they feel. I think this is part of the point that you're making, this crisis of values. We have so many clinicians in practice for 30 years who've lost their sense of purpose and connection to what brought them to medicine in the first place. Most of the young people going into medicine now, unlike many years ago, are not guaranteed huge, six-figure incomes, even in the States. So they could go into a lot of other professions, they could make that choice and make a great deal more money. They're there because something is calling them with a great deal of purpose and I believe, ultimately, it is exactly what Lévinas is pointing to, the response to the suffering other.¹⁹¹ But that can very quickly become erased when one is in practice. The interesting thing is that every year we're getting more applicants to our Master's programme right out of their undergraduate education, so they know now before going to medical school that this is going to happen, that this is a danger. They are, and they speak this way, anxious to inoculate themselves in some sense. We're hearing now from our students in medical schools about the difference it made to them to have studied rigorously this work and what it means and the differences they see between themselves and their peers. And it really does, in a nutshell, come down to this question of values, remaining connected to the sense of purpose that brought them to the field in the first place.

Macnaughton: Yes, I think there's a parallel crisis in this country that's particularly been mentioned recently as a crisis of compassion. There have been an awful lot of conferences, and it follows on from the Francis report on the Stafford

¹⁹¹ See note 189.

Hospital problems.¹⁹² I think the background to this is again, somebody earlier mentioned the importance of institutional structures in driving the way things are. The medical profession in this country has given up responsibility, is taking more for doing less according to patients, and I think this applies to general practice and it is criticized in that way by the patient population. It is seen as not being as caring and compassionate, not being prepared to go the extra mile. So it's our fault, and so people are cynical about the great declarations of compassion and care that we make and this has happened with the nursing profession as well. This has been a big problem there too so, for example, just two weeks ago I was speaking at a conference on compassionate healthcare.¹⁹³ People are desperate to know, 'How can we go back? How can we retrieve a sense of people trusting us to care?' One of the big problems we have is that we now rely on a managerial system that wants to provide safety nets for everything. As we know from the recent work of philosopher Havi Carel,¹⁹⁴ who draws upon the Continental tradition of Heidegger and others, human nature is fluid and is subject to change and adaptation in unexpected and difficult circumstances, so it is not possible or even desirable to have safety nets for all actions by clinicians in healthcare settings. We can't have a safety net for everything; we can't have a managerial system that will anticipate everything that will happen, so people need to have a professional 'something' inside them which relies on trust and which they will trust people to practise the good skills in a caring fashion. So we've got a real struggle to change the institutional structures in which we work in the NHS and within these care situations because otherwise we will not be able to work in this way; it militates against compassionate care.

I know we've been talking about narrative structures but I think there's an awful lot that's broader. A lot of people have talked about the atmosphere of your institution and this is terrific. There's the sense of something seeping through your teaching of the medical students into the structures within which you

¹⁹² The Francis report was the result of an inquiry into the failings of the Mid Staffordshire NHS Foundation Trust to provide adequate standards of patient care at Stafford Hospital: 'Between 2005 and 2008 conditions of appalling care were able to flourish in the main hospital serving the people of Stafford and its surrounding area'; quoted from The Mid Staffordshire NHS Foundation Trust Public Inquiry (2013), page 7. See also Hughes (2013) and O'Dowd (2013).

¹⁹³ 'Compassion in Primary Healthcare: Conflicts, politics and opportunities' conference at the Royal College of General Practitioners; <http://www.rcgp.org.uk/courses-and-events/scotland/rcgp-scotland/ethics-conference.aspx> (visited 19 June 2014).

¹⁹⁴ Carel (2008).

are working. This word ‘atmosphere’ and the word ‘environment’ came up again and again in the Francis report about environments of lack of care, of atmospheres of fear, but to me that sense of an emotional atmosphere: How do we create it, how do we change it? These are questions for medical humanities; it’s not about narrative, it’s about, what are the emotions that are pervading that atmosphere? What are the values? And that’s about relationships, which to my mind aren’t just to do with the stories we tell, it’s to do with feeling and how feeling is picked up and responded to. So I think we’re talking about a much broader set of issues.

Brockmeier: I agree with everything that you said, Jane, I just wanted to emphasize that we don’t necessarily have to subscribe to this juxtaposition of compassion, emotion, and empathy on one side and narrative on the other.¹⁹⁵ Many people would say that you can only understand how narrative works if you understand exactly these emotional qualities whose importance you have rightly emphasized. They are inherent to how stories work, they are part and parcel of narrative understanding, which also means the understanding of a narrator.

Spiegel: In working with medical students, I make a point of telling them that I’m not trying to teach them to be compassionate. That is not the project.¹⁹⁶ They recoil from what they perceive as our presumptuousness and its implications about who they are. Instead, my approach is to use films to urge them to take notice of their own responses and reactions – their experience of the films.¹⁹⁷ So it’s about using narratives – I use movies, they are so emotion-driven, they create sensations and sometimes sensations that students don’t want to have.¹⁹⁸ I’ve observed that medical students sometimes get angry at a film because the

¹⁹⁵ Professor Jens Brockmeier added, ‘I think narrative is profoundly about compassion and about intersubjectivity more generally.’ Note on draft transcript, 4 November 2013.

¹⁹⁶ Professor Maura Spiegel wrote: ‘They are sometimes suspicious at the start, believing that is why we (we humanists) are there, to teach them to empathize.’ Note on draft transcript, 4 December 2013.

¹⁹⁷ The films that Professor Spiegel uses include *The Savages*, director Tamara Jenkins (2007), Fox Searchlight Pictures, and *Decalogue 1*, director Krzysztof Kieslowski (1989), Polish Television.

¹⁹⁸ Professor Maura Spiegel elaborated: ‘In discussion they identify moments where they are turned off to a character, and perhaps where they feel self-critical about turning off, fearing or feeling guilty about their judgments and what they feel might be their failure of compassion. And these are productive things to talk about and write about because the vicissitudes of sympathy are very much on their minds as they begin to have contact with patients. What behaviours in the clinic arouse judgments? What gets to you? What leaves you cold?’ Note on draft transcript, 4 December 2013.



Figure 15: Professor Maura Spiegel

filmmaker is too kind to the characters. It's a surprising thing. What's more, we attempt to explore what is taking place in the room at the very moment, to take note of the atmosphere, what can be spoken, what is difficult to speak about and why. In what contexts is it impossible to speak or to speak up, to address a perceived wrong? Much of our work is about changing group dynamics, working with teams of clinicians to try to open up a different way to speak to one another, to allow for questioning and even doubts. And, as Rita would say, we use a literary or film text to get underneath the language they're accustomed to using, to alter and enrich the very language, the words themselves. And to speak in a different way to one another can be culture changing.

Frank: Jane makes an absolutely crucial point and Jens provided a really beautifully articulate answer. The simplest form to me is, if I have to explain to someone, like the anthropologist from Mars, what any of these words like compassion or whatever is, sooner or later I have to tell them a story. If they keep saying to me, 'I just don't get it', I have to tell them a story and if they don't get the story then they're just not human. [Laughter] We would think there is a problem in their fundamental humanity. The other side of it is, if you start with a story, and you really ask what's going on in the story, sooner or later you will get back to these basic words that Jane Macnaughton listed very well and you'll find that is what the story is about.

I want to take this all the way back, it's a big circle I know, but all the way back to where Kathryn started, when you said you were dissenters from formalism.¹⁹⁹ What you see is the use of literature in a particularly non-literary-critical way. In these programmes, where to me a lot of the value of how 'literature' is presented, and generally how stories are presented, is just in terms of the way in which parents and children tell each other stories. Their interest is how do these teach you how to be human? So much literary criticism – I think everything we could gloss under Kathryn's term formalism back then and into the present – has lost track of the fundamental impulse of stories, which remind us of the obligations and responsibilities that we have to each other as human beings. That, to me, is why we tell stories, to constantly bring these understandings back into the foreground because they're constantly being threatened by all manner of bad behaviour. Maybe the bad behaviour has to do with budgets, and maybe it has to do with just a fundamental human potential for cruelty, but we tell ourselves stories to rescue ourselves over and over again.

Launer: One of the practical pieces of work I'm doing at the moment is working with teams of clinical teachers in hospitals in London who scored very poorly on the National Training Survey for bullying and undermining.²⁰⁰ So we get reports from their trainees, sometimes statistical, sometimes anecdotal whistleblowing at assessment panels and so on. And the work I do with these teams of clinical teachers is essentially narrative work. I go into a group of pathologists or paediatricians or anaesthetists, often with a co-facilitator, and you know what? We hear narratives of suffering. I mean, we hear narratives of how they're suffering because of clinical workload, because of the unmanageable tensions between clinical service and training, because of bullying managers, because of resource shortages, because of, organizationally, configurations that haven't been properly managed and have just been imposed on them. I don't see the work we do with them fundamentally as any different from family work, or group work, or any therapeutic work one does using a medium of stories. It's self-evident that we don't use poetry, we don't get them to read novels, we don't get them to watch movie clips, and we certainly don't talk about compassion but I think what we are doing is using their narratives to restore some sense of compassion among them, hopefully.

¹⁹⁹ For Professor Kathryn Montgomery's comments on formalism see page 6.

²⁰⁰ For the survey report that 'asked doctors in training if they had experienced bullying or undermining in their workplace', see General Medical Council (2013), available to download at http://www.gmc-uk.org/NTS_2013_autumn_report_undermining.pdf_54275779.pdf (visited 16 May 2014); quotation from page 1.

Irvine: I just wanted to tell a story again, to illustrate some of these points and how narrative medicine is enacted. For over a decade, I have worked with the Family Medicine Inpatient team and every week they gather for what we call narrative medicine rounds, sit-down rounds first thing in the morning with the entire team so the attending physicians, the interns, the residents.²⁰¹ We read together poems, short stories, we discuss the piece, I have them write to a prompt. On this particular day they were discussing a patient, they were all completely preoccupied when I came in. He was a sickle-cell patient, a young man in his early 20s, and the characterization was that he was a drug seeker and he was back for his, I don't know, eighth admission that month, everybody was fed up with him, they were very angry, and the discussion was centred around how to get him out as quickly as possible. The sense of lack of compassion was palpable, but these are very busy interns and residents and it's probably the twentieth patient that they've had in this very busy urban, inpatient service. And so we did a simple exercise and this will be familiar to many of you: we had them write each from a different perspective. So one of the interns wrote from the mother's perspective, one of the other interns wrote from the patient's, a first-year resident wrote from the attending physician's perspective, the attending physician wrote from the resident's position, somebody else from the social worker's position, and then they read their narratives to each other. After reading each of them we talked about what they had written and, in the way that we do, the way they constructed the story, how was time shaped in the story, what metaphors they used. Really trying to work through what they had revealed about their feelings, about that perspective, making it very clear that we're not assuming that they're pretending to know what was going on from that person's perspective but using their creative imaginations to try to engage with the story. Of course, the mother of the patient happened to be a nurse who worked in the hospital and when the intern, who was one of the people who was most angry at the patient, inhabited that position, she wrote a story about her son when he was a little boy: every time he was admitted in the paediatric service, everybody was so nice, they were so understanding, they were so beautiful to him, and now when he's an adult everyone seems angry, they're always yelling, they treat him like a piece of trash. There was a great deal of feeling in the room as this resident was reading, and a great deal of feeling when discussing the piece – we weren't principally interested in doing any kind of therapy but the way that feeling through the narrative acts on that team, the way it acted, was palpable. It was a complete reorientation toward the patient, so then when they go in an hour to walk into that patient's

²⁰¹ The Family Medicine Inpatient Service, Columbia University Medical Center.

room they walk in with a very different perspective. You know if it were just an ethics case, of course, and we were dealing with abstract principles, we'd be debating whether beneficence was the prevailing value here or non-maleficence, not doing any harm in giving him the drugs, or the patient's autonomy. But all of that means nothing in the face of what, of course, Art Frank calls 'thinking with the story'.²⁰² The point is that it is through the narrative that one engages with these issues of feeling and compassion and reorienting perspective.

Hurwitz: 'Thinking with the story' is something that John was just now talking about.

Launer: Very briefly, one of my favourite distinctions has been made by a Californian therapist called Lois Shawver who talks about the difference between listening in order to speak and speaking in order to listen.²⁰³ Listening in order to speak being what doctors do most of the time, in order to chip in and say, 'Well it sounds to me as if...' or 'You're saying what is going on is X, I'm telling you what is really going on is Y.' Speaking in order to listen is solely making utterances in order to create a narrative space for the person or people that you're interacting with to continue their stories.

Elder: Just following what John was saying, and Jane earlier, and the word listening is now being used much more freely. I speak almost entirely from a UK, largely general practice, NHS context, so who is listening to the doctors at Mid Staffs?²⁰⁴ Who is listening to the staff, the nurses, everybody else?

The word 'story' has a very benign atmosphere, but of course what we're talking about is listening to stories that are extremely disturbing to listen to. It's obvious and very familiar to everybody in this room, but the consequences of listening to traumatized stories are themselves traumatizing and so when you're then dealing with traumatized practitioners and institutions that are also caught up in that kind of environment. Man hands on misery to man and cruelty is passed on and all the other negative things that we're familiar with get passed on. I want to liken that to the idea of transformational change within the medical establishment because much that's gone on in the last 20 to 30 years is to do with constructing small, helpful add-ons but things that don't fundamentally change the culture or fundamentally change the mindsets with which people

²⁰² Frank (1995), pages 23–5.

²⁰³ Shawver (2012).

²⁰⁴ See pages 61–2 and note 192.

practise. One of the things that I do at the moment is listen to medical students just down the road at UCH (University College Hospital), and listening earlier to the stories that people were talking about, distressing experiences on the wards when they were students in the 1970s or 1980s, has it changed? The stories I hear are highly reminiscent of the ones I experienced in the 1970s. Is the atmosphere better? I'm not sure. Medical schools are bigger, they're busier. When we start a discussion group now with third year medical students they don't know each other, we usually just have to introduce them and say, 'Are any of you doing the same firms? It's often the beginning of any relationship between the students. In our day, at least we knew each other.

There are big question marks about what needs to change and what hasn't changed and what listening is it, early on and then continued throughout, that is capable of producing a robust change within the practitioner that enables you to continue a listening practice or some kind of humanity in response to the work that you're doing, but is sufficiently robust to carry you through what's going to be many, many difficult experiences in an environment that's often going to be not conducive to that kind of practice.

Frank: I just want to follow that. They're not only stories that are traumatic. Again, this work takes place against a political background that we all live in and that influences us. As I've worked on narrative in the twenty-first century, the political background that had to influence me massively was international terrorism and what I would call sectarian conflicts. I had to come to the recognition that if you want to find a group that really do think with stories, my recommended stance in *The Wounded Storyteller* is look at a terrorist cell; look at a sectarian conflict.²⁰⁵ These are people who are thoroughly caught up in their stories, and stories are on the parameters of their thoughts. The context has changed since the mid-1990s when, going back to what Andrew said about using stories in a much more benign sense, recognizing how deeply traumatizing they were but seeing that trauma as part of the human condition that we had to learn to live with. In this century, I've had to create a rather different category of what I would call 'dangerous stories' and we could go back to that in terms of the work that John is doing with abusive physicians, because I suspect a lot of the stories that they start off telling at the beginning of your groups are ones that you really don't want anybody to think with, because they're simply dangerous. So one of the huge shifts to me, insofar as we have stopped this seminar at the Millennium and the Millennium was fairly quickly followed by the, 'we're right

²⁰⁵ Frank (1995).

now in the century of the “war on terror” in various ways’.²⁰⁶ Thus, the category ‘dangerous stories’ has to be brought in. For all of the testimonial things that I and others have said about how great stories are, I had a chilling experience once when I was asked to referee a journal submission. It was for poems that medical students had done in a course much like the ones we’ve talked about. One was a vindictively blaming poem about all of the bad health habits of this particular patient and the final lines were: ‘And when you get sick, don’t come to me to take care of you.’ And my referee comment was, ‘So what did you, as the course instructor, do with this?’ You are just presenting us with these poems to publish in this journal but part of the story to me is: how did you respond to a student who turns in a story that I don’t want people thinking with? I never got an answer to that question. I think that part of the challenge of this work, in narrative medicine, is identifying and responding to stories that you don’t want your students thinking with.

Hurwitz: I think this is one of the points that Craig was making about undoing a story and clearly some stories need to be undone, sometimes a difficult process.

Montgomery: I want to go back to the issue of marginal improvement and Jane’s challenge to the incremental bits that don’t really add up to anything. I’ve spent 25 years thinking about how doctors use stories to think with and it’s not something that we need to recommend to them; they do it. And yet, every now and then I see that recasting medicine as fundamentally narrative, as Brian and Trish Greenhalgh did in that book 12 to 13 years ago, *Narrative Based Medicine*,²⁰⁷ that might be the re-centring that’s needed. Build the science around it, then build the narrative medicine skills based on that. But at the same time, as near as I can see, medicine is peculiarly resistant to epistemology, to philosophy. Pierre Bourdieu says that, in practice, people go with the information at hand and they treat it as the complete body of knowledge.²⁰⁸ You can’t as a practical person engaged in action, simultaneously question the status of your knowledge, and yet that’s what we’d be asking them to do if we centred medicine on narrative, if we recast medicine as a narrative practice that draws in evidence as one kind of

²⁰⁶ In the aftermath of the 11 September 2001 attacks on the World Trade Center in New York, the then President of the USA, George W Bush, declared to Congress that America was launching a ‘war on terror’. The transcript of his speech was published by *The New York Times* on 21 September 2001; <http://events.nytimes.com/2001/09/21/national/21BTEX.html?pagewanted=print&module=Search&mabReward=relbias%3Aw&r=0> (visited 23 July 2014).

²⁰⁷ See note 180.

²⁰⁸ Bourdieu (1990), pages 26; 91.

narrative and draws in clinical experience and even intuition as the rest of it. So this remains a puzzle for me and I'm interested in Jane's suggestion because I've never thought of that, but I'm kind of at a dead end. I'd like to hear from Brian and also from Trish about what sort of foothold narrative based medicine is.

Hurwitz: I'm very sorry that Trish isn't here.²⁰⁹ One of the points often made about medical scientists and doctors in relation to narrative is that they can be some of the most committed naive realists in the world. The danger of narrative getting into the hands of naive realists is that they think it's representational and only representational. So this is one of the other dangers of narrative; it's not just the bad narratives that need to be undone but it's the kind of metaconception of what narrative is that needs to be addressed.

Charon: That's why it needs to be taught well at a high disciplinary level, with rigour. Years ago I decided that no one would teach my medical students without a terminal degree in any field related to narrative medicine education. I didn't want paediatricians whose hobby was teaching poetry. And that's why I gathered with Craig and Maura and a few others in my team. It's hard. We don't teach William Carlos Williams and Anton Chekhov just because they're doctors, and we make it hard and we show our students, whether they're the Master's students or medical students or nurses, dentists, that to read and to write are acts requiring tremendously strenuous intellectual, cognitive, creative powers and that you have to learn how to do it. That's not to suggest that their mummies didn't read them stories when they were babies but there is that which must be learned.

Brockmeier: I wanted to connect this nice remark on naive realism that you just made, Brian, to the big battle cry in many statements dismissing the epistemological status of narrative and narrative research, as qualitative in contrast with 'evidence' or 'evidence based' research. This is an old argument, an argument that claims a different epistemological status for 'evidence based' medicine, neurology, psychology, and so on. Over the last couple of years, I have visited, a few times, the Swedish Center for Dementia Research.²¹⁰ It's amazing

²⁰⁹ See Professor Trisha Greenhalgh's introduction, pages xiii–xvii and biography on page 82.

²¹⁰ See the Center's website for further details of its research: <http://www.isv.liu.se/ceder?l=en&sc=true> (visited 12 August 2014). Professor Jens Brockmeier commented, 'This is quite an unusual institution. It is well equipped although it concentrates on qualitative research, including narrative-based studies, conversation analysis, and ethnography, involving researchers from a broad spectrum of disciplines.' Note on draft transcript, 4 November 2013.

how little research is being done about how people suffering, and coming to terms with, dementia, how little we know about the experience of dementia as a subjective phenomenon.²¹¹ Somebody said earlier, ‘we never read about patients’.²¹² Why is that so? One reason might be that 95 per cent of all money spent in this area goes into biochemical research on how the brain’s plaques and tangles work.²¹³ So this is evidence. In the meantime, a steadily growing part of the population will be affected by this disease, probably for the next 30 to 40 years, and will live with it for part of their lives.²¹⁴ The tests almost always focus on the individual brain and they focus on ‘its’ failures and shortcomings. The person of course knows that, and reacts and behaves exactly as we would do if we were assessed under such test conditions. But working with people under normal everyday conditions, where they are best, requires a different approach; and it requires a different notion of evidence – different from the notion of evidence produced under lab conditions and in neuropsychological tests. Similar studies, based on different notions of interactional and embedded evidence are being done in various parts of the world, although it might not be a coincidence that the Swedes are leading in this area of research.²¹⁵ I believe that there are more areas, pockets of ‘alternative evidence’ that even speak to the naive realist that Brian mentioned before.

²¹¹ For two personal accounts of having dementia, see Saunders (2013), excerpt available at <http://garev.uga.edu/winter13/saunders.html>, and Pratchett (2013); <http://www.dementiablog.org/terry-pratchett-on-dementia/> (both websites visited 13 August 2014).

²¹² See page 14.

²¹³ See, for example, the UK-based Brains for Dementia Research project for further details of current biomedical research; <http://www.kcl.ac.uk/iop/depts/oldage/research/bdr.aspx> (visited 13 August 2014).

²¹⁴ Professor Jens Brockmeier wrote, ‘And we have to do something with these men and women. We cannot just say, “one day our evidence-based work done in our labs will yield helpful results, unfortunately for the time being we can’t help you”. In fact, we can help many of them, at least within certain limits. Among others, we can help them with research – like that done at the Swedish Center – which, although often dismissed as qualitative, allows us to understand what it means to be assessed as a dementia sufferer and nevertheless live a human life, a life with dignity. For example, the Swedes found out that all common neuropsychological tests not only assess, but also produce certain symptoms. The brains of people work differently when they are assessed under neuropsychological test conditions – in which they typically are individualized and socially isolated – or when they operate in familiar everyday life contexts, that is under conditions of normal social interaction, where their spouses or care persons support, encouraged, and involve them to do things.’ Note on draft transcript, 4 November 2013.

²¹⁵ Professor Jens Brockmeier added, ‘[This is an area] where people do not want to wait until “truly” evidence-based experimental brain research has solved the problem, assuming it will be able to do so.’ Note on draft transcript, 4 November 2013. See Hydén, Lindemann and Brockmeier (eds) (2014).

Macnaughton: Something that Rita said about the interested amateur, and this is another shift that's gone on in this past decade; we have shifted from the interested amateur delivering medical humanities in universities to people who have got the background and the training. One of the things that brings me to, is the role for the Wellcome Trust, which I think needs to be mentioned in terms of, in this country, providing really quite significant funding to support the development of this field and the throughput of new, young scholars. That is just crucially important for us. We need new people coming through that are going to take this field on and develop it into the future, and that is something that the Wellcome Trust is doing and really providing a background for, because our universities are not investing in this field. I think that the Wellcome Trust is playing a huge role in helping us to move on in developing an evidence base that brings bioscience and the humanities together. I'm thinking particularly of the 'Hearing the Voice' project that we have in Durham, which is looking at the experience of hearing a voice that's not there, which those of us who are clinicians think of as a delusional thing related to the diagnosis of schizophrenia but, which some studies reported, 13 per cent of the population experience it, many without a diagnosis of schizophrenia.²¹⁶ So one of the things, in terms of the project that we are doing, which is bringing literary scholars, phenomenologists, clinical psychologists, psychiatrists, scientific psychologists, and neuroscientists together, to start to think about: 'Well, what kinds of questions should we be asking people sitting in a functional brain scanner that we haven't asked about people who are experiencing voice hearing before?' For example, most of the studies have been done on people who have been medicated. What difference is that going to make to their brain before you start to ask them? Most of the questions ask, 'What is it your voice is saying?' Well, voices can be loud and soft, can be frightening or not frightening, they can be recognizable to the hearer or not recognizable to the hearer. There are so many elements to the experience that the bioscience perspective does not question. So that's what our literary scholars, our philosophers, are now doing for what seems a very kind of esoteric field. I thank the Wellcome Trust hugely for giving us the opportunity to do that.

Hurwitz: In the UK at least, it's not only the Wellcome Trust, other research councils are also interested in this sort of multidisciplinary study of, say, a symptom, or a set of symptoms. I think that we're moving towards a natural

²¹⁶ Hearing the Voice is an ambitious, interdisciplinary research project that aims to provide a better understanding of the experience of hearing voices in the absence of any external stimuli (termed 'auditory verbal hallucinations' in a medical context)', quoted from the project's page on Durham University's website; <https://www.dur.ac.uk/hearingthevoice/> (visited 5 June 2014).

pause, perhaps even a natural end. And just to bring some of these threads together, it is striking how hopeful we are of greater awareness of how narrative works at multiple levels, sometimes very formalistic and other times informally and untheorized.

Frank: We're back to a version of the dilemma, at least I hear us being back to a version of the dilemma I mentioned before. Part of why this all started was a reaction against medicine being defined by technique. Jane, you spoke to this earlier when you said everything has to be taught.²¹⁷ It's as if you have no normal human capacities anymore, you can only take a prescribed course of action that's been laid out somewhere. It all begins as a reaction against technique but then you know a problem any of us have – Rita has it writing *Narrative Medicine*,²¹⁸ I have it writing my things – is that you need to be able to give people categories, you need to organize your text. Therefore, you start coming up with things that begin to sound kind of prescriptive, even though the whole point is that you don't want to be prescriptive, you want to leave this open and this, to me, is just one of the ongoing tensions of how any of us write, teach, speak. It's the balance we try to find between somehow organizing practices, and providing categories of practice that can help orient other people, versus not providing too much. I think it's fair to say that a lot of clinical–medical teaching micro-manages, it prescribes in far too great a detail. In the last couple of years I've participated in two anthologies of essays on Aristotle's notion of phronesis – practical wisdom acquired through experience.²¹⁹ I think one reason people are so interested in phronesis is that it's an anti-technique technique. It's a word that we can use to locate what we're doing but then once you've used the word to locate what you're doing, things open up again and there's no prescription for how you do phronesis. It's this verb 'doing' that I hear over and over again, particularly in methodology, as in 'I'm doing narrative', or 'I'm doing phenomenology'. I imagine you have nightmares about somebody saying, 'I'm using narrative medicine'. That's just the tension we live with and it's where your call, Jane, for younger scholars is really important. As we get older, we may reach a point where somebody has to take it over and undo the things we've done and put them back together again, and that's a good natural order of things to me.

²¹⁷ See pages 25–6.

²¹⁸ Charon (2006).

²¹⁹ See, for example, Flyvbjerg, Landman and Schram (eds) (2012).

Hurwitz: Well, thank you all very much indeed. It's been a very stimulating and engaging conversation. I want to thank the team from Queen Mary and Tilly Tansey in particular for allowing us the opportunity to have this conversation and have it in a way that's recorded and that will be followed up with a transcript and with further research.

Tansey: Well, thank you all very much for coming and telling us your stories. It's been a particularly resonant meeting for us because, as I said at the beginning, we mainly do biomedical science, so this has been a very different kind of meeting for us and, of course, I realise that we 'do' narrative medicine very largely. Like so many of our meetings, I feel that we're only just beginning. It's been a fascinating afternoon hearing all your stories and I know that we can't actually have another Witness Seminar but I know that many of you are staying in London for Brian's conference, so I hope that some of the stories and some of the ideas that have been engendered now will carry on and perhaps at a later date we might be able to have a further meeting.²²⁰ I would like to thank our chairman in particular because this was Brian's idea. He has advised us on inviting all of you people here, and I think it's been an extremely successful and fascinating meeting. So thank you very much indeed, Brian. [Applause] Thank you.

²²⁰ See note 1.

Appendix 1

Outline of narrative medicine's development at institutions and by individuals in the USA and UK²²⁰

Pennsylvania State University College of Medicine (Hershey)

- 1967** First department of humanities established at a medical school
1972 Joanne Trautmann Banks appointed Professor of Literature

Morehouse College (Atlanta)

- 1967** Kathryn Montgomery teaches English literature in medical education
1977 Founds medical humanities programme in new medical school

University of Texas Medical Branch (Galveston)

- 1973** Institute for the Medical Humanities founded
1979 Anne Hudson Jones develops literature and medicine programme

University of Rochester School of Medicine and Dentistry (New York)

- 1980** Kathryn Montgomery founds Division of Medical Humanities

Johns Hopkins University (Baltimore)

- 1982** Journal *Literature and Medicine* launched

Feinberg School of Medicine, Northwestern University (Illinois)

- 1988** Medical Humanities and Bioethics Program founded – Kathryn Montgomery Co-director, later Director

²²⁰ This outline has been compiled from details within the main transcript combined with information derived from Bleakley and Jones (2013).

University of North Carolina

1988 Larry Churchill becomes Professor of Social Medicine

UK

1998 *Narrative-Based Medicine* by Trisha Greenhalgh and Brian Hurwitz published (Greenhalgh and Hurwitz (eds) (1998))

Columbia University (New York)

2000 Rita Charon establishes a narrative medicine programme

2002 Craig Irvine appointed Director of narrative medicine programme

King's College (London)

2002 Brian Hurwitz appointed Professor of Medicine and the Arts

UK

2002 Association for Medical Humanities founded – Jane Macnaughton is a founder member

Dr John Launer's *Narrative-based Primary Care* published (Launer (2002))

2008 Centres for medical humanities established at King's College London and Durham University

Columbia University (New York), King's College (London)

2013 International narrative medicine conference, 'A Narrative Future for Healthcare', Guy's Hospital. Organizers: Brian Hurwitz, Rita Charon, and Neil Vickers²²¹

²²¹ See note 1.

Appendix 2

Balint: an afterword by Dr Andrew Elder²²²

When I became a GP in 1972, by far the dominant tradition advocating the ‘human face of medicine’ or ‘whole patient medicine’ was that started by Michael and Enid Balint.²²³ Their work centred on a narrative account of the doctor–patient relationship and arose from collaboration between psychoanalysts and doctors. It does not employ the (much later) language of narrative medicine. Just as Kathryn Montgomery spoke of how careful she and her colleagues were not to teach any literary theory, encourage particular texts, or mention off-putting intellectual ideas, Balint was scrupulous not to mention psychoanalytic concepts, or use psychoanalytic language. His approach was about listening, and encouraging the development of professionals’ authenticity, not teaching. He created his own metaphors with which to encapsulate his approach – perhaps most notably the ‘drug doctor’, and his consequent invitation to study the uses and abuses of this ‘drug’ since it was the most often prescribed and least studied one in clinical practice.²²⁴

As far as its intellectual origins are concerned, Balint’s work is the clear link to the Continental tradition so clearly articulated by Jens Brockmeier: Michael Balint was trained in the Hungarian tradition of Freudian psychoanalysis, a pupil of Ferenczi, and both were pioneers in the development of understanding of the mind–body relationship and in the development of interpersonal aspects of psychoanalysis. Balint brought this tradition to the UK just before the Second World War and then developed his thinking at the Tavistock Clinic in the 1950s along with his wife Enid, also a psychoanalyst, who had been working with social workers and seeing patients with marital problems. Balint groups are widely employed in the training of doctors throughout Continental

²²² Dr Andrew Elder wrote this text on Balint after the seminar, expanding his point about his significant influence on the development of narrative practices in medicine in the UK. Email to Professor Brian Hurwitz, 24 June 2013.

²²³ For Michael Balint, see note 26. For Enid Balint, see, for example, Balint and Norell (eds) (1973).

²²⁴ Dr Andrew Elder further commented: ‘The “drug doctor” was a central concept of Balint’s, that the drug doctor, i.e. him/herself, was the most frequently prescribed “drug” and its uses needed to be studied more systematically, in other words how to use “self” in the practice of medicine, its therapeutic effects and of course side effects.’ Email to Ms Emma Jones, 22 August 2014.

Europe, but also USA and (now recently) China. There are 23 countries with societies affiliated to the International Balint Federation. It remains an active approach to ‘narrative’ medicine: in training, research, morale restoring, and in organizational teamwork.

In the UK there is also a clear, sustained body of narrative research (or action research) developing the Balints’ work from the 1970s onwards: the key publications run from 1957, 1973, 1987, 1993, and 2000.²²⁵ As far as the influence of the Balints’ work is concerned, in the UK it is mainly seen through its effect on the development of general practice from the 1960s onwards. It had a major impact on the intellectual foundations, early work, teaching programmes, and later attitudes of the (Royal) College of General Practitioners and similarly on vocational training for GPs, and to a lesser extent on undergraduates. There was a more limited influence on hospital specialists but recently Balint groups have become a mandatory component of training for psychiatrists. There is a large secondary literature about GP training that is influenced by the Balints’ thinking.

²²⁵ See, for example, Elder and Samuel (eds) (1987); Balint *et al.* (1993).

Biographical notes*

Professor Jeffrey Aronson

MA DPhil FRCP FBPharmacolS FFPM (Hon) (b. 1947), trained in the University of Glasgow (1964–1973) and the Medical Research Council Unit and University Department of Clinical Pharmacology, Oxford, under the late Professor David Grahame-Smith. He is currently Reader in Clinical Pharmacology at the University of Oxford and Honorary Consultant Physician in the Oxford University Hospitals Trust. He was President of the British Pharmacological Society (2008/9) and is now Emeritus President. He was Vice-chairman of the Medicines Commission (2002–2005) and Editor-in-chief of the *British Journal of Clinical Pharmacology* (2003–2007). He has been Chairman of the British Pharmacopoeia Commission's Expert Advisory Group on Nomenclature since 2006. He was a member of the Formulary Committees of the British National Formulary from 2006 and the British National Formulary for Children from 2003, and is now a member of the Advisory Board of the British National Formulary.

Dr Catherine Belling

PhD (b. 1965) is Associate Professor of Medical Humanities and Bioethics at Northwestern University Feinberg School of Medicine. Her current research reads 1970s medical suspense fiction and film as an anxious popular reflection of the emergence of bioethics. Her first book, *A Condition of Doubt* (Belling (2012)), won the 2013 Kendrick Book Prize (Society for Literature, Science, and the Arts), and one of her articles, 'Narrative oncogenesis: The problem of telling when cancer begins' (Belling (2010)), won the 2010 Schachterle Prize. She is editor of the journal *Literature and Medicine* and has served on the Board of Directors of the American Society for Bioethics and Humanities.

Professor Jens Brockmeier

PhD (b. 1951) received his degrees in psychology, philosophy, and linguistics/literary theory from the Free University Berlin where he also was awarded his Habilitation and took on his first appointment, in 1978, as Assistant Professor of Epistemology and Philosophy of

* Contributors are asked to supply details; other entries are compiled from conventional biographical sources.

Science. Since then, he worked at various universities in Europe and the Americas. Before his present appointment as Professor of Psychology at the American University of Paris, he served, among others, as Visiting Professor in the Graduate Faculty of the New School, New York (2002–2005), in the Department of Human Development at the University of Toronto (1995–2002), and the Psychology Department at the University of Manitoba in Winnipeg (2005–2013). As a Senior Visiting Member of Linacre College, Oxford (1992–1996), he taught at the Philosophy Centre of Oxford University. His research is concerned with the cultural fabric of mind and language. One of his main interests is in narrative as linguistic, psychological, and cultural form and practice.

Professor Rita Charon

MD PhD (b. 1949) trained at Harvard Medical School in 1978, completed primary care internal medicine training at Montefiore Hospital's Residency Program in Social Medicine in 1981, and enrolled in the General Medicine Fellowship at Columbia University/ Presbyterian Hospital. Upon completion of the fellowship in 1982, she was appointed to the Department of Medicine at Columbia as Instructor in

Medicine and has remained at Columbia since, achieving full professorship in 2001. She was awarded a PhD in English from Columbia University in 1999, writing a dissertation on the late works of Henry James. She received a Rockefeller Foundation Bellagio residency in 2000, a Guggenheim Fellowship in 2001, and funding from the National Endowment for the Humanities in 2002 to support the emergence of what she named Narrative Medicine. She founded and is the Executive Director of the Program in Narrative Medicine at Columbia and has had 10 years of NIH-supported research in faculty development and curricular development in narrative medicine. She has an active and near-uninterrupted practice of general internal medicine at the Presbyterian Hospital.

Professor Larry Churchill

PhD (b. 1945) was Department Chair of Social Medicine at the University of North Carolina (UNC) at Chapel Hill from 1988 to 1998 where he played a major role in developing medical ethics programs at UNC. In 1991 he was elected to the Institute of Medicine, National Academy of Sciences, and, in 2002, was made a Fellow of the Hastings Center. Since 2002 he has been Ann Geddes Stahlman Professor of Medical Ethics at

Vanderbilt University, Nashville, Tennessee. His recent research has turned from policy questions and ‘big-decision’ ethics to the moral features of routine medical care. His most recent books develop his research findings in this area: *Healers: Extraordinary clinicians at work* (Schenck and Churchill (2012)), and *What Patients Teach: The everyday ethics of health care* (Churchill *et al.* (2013)).

Dr Andrew Elder

MD (b. 1945) was an inner city general practitioner in Paddington from 1972 to 2008. He has a longstanding interest in the doctor–patient relationship, the Balint tradition, and in all aspects of counselling and psychotherapy in primary care. He has written and lectured widely on these subjects. He first became a member of a Balint group in 1972 and later collaborated with Enid Balint in research and training groups and published two books resulting from this work. He was President of the (UK) Balint Society from 2007 to 2011 and now chairs an international group of Balint leaders who host international workshops on Balint group leadership under the auspices of the International Balint Federation. Throughout his career as a GP he worked as a trainer and educator and was

appointed Consultant in GP and Primary Care at the Tavistock Centre in 1995. He was co-chair of the Primary Care section of the Association of Psychoanalytic Psychotherapy in the NHS and was a founding committee member of the Association for Infant Mental Health. He now works as a Consultant in General Practice and Primary Care (Marlborough Family Service), Balint Group leader, and writer.

Professor Arthur Frank

PhD (b. 1946) trained as a medical sociologist at Yale University. He is the author of a memoir of critical illness, *At the Will of the Body* (Frank (1991)); a study of first-person illness narratives, *The Wounded Storyteller* (Frank (1995)); expanded edition, 2013); a book on care as dialogue, *The Renewal of Generosity* (Frank (2004)); and, most recently, a book on how stories affect our lives, *Letting Stories Breathe* (Frank (2010)). Dr Frank has been Visiting Professor at the University of Sydney, Ritsumeikan University in Kyoto, Keio University in Tokyo, and the University of Toronto, and a Visiting Fellow in Bioethics at the University of Otago, New Zealand. For many years he was book review editor of the journal *Health: An interdisciplinary journal*, and, among other editorial board

appointments, he is a contributing editor to *Literature and Medicine*. Dr Frank is an elected Fellow of the Hastings Center and a Fellow of the Royal Society of Canada. He was the 2008 recipient of the Abbyann Lynch Medal for Bioethics, awarded by the Royal Society of Canada. He is Professor Emeritus of Sociology at the University of Calgary, where he has taught since 1975, and a professor at Betanien College of nursing, Bergen, Norway, which is starting a narrative nursing programme.

Professor Trisha Greenhalgh OBE FMedSci (b. 1959) studied medical, social, and political sciences at Cambridge and clinical medicine at Oxford before training as an academic GP. She is Professor of Primary Health Care and Dean for Research Impact at Bart's and the London School of Medicine and Dentistry, London, UK. She leads a programme of research at the interface between the social sciences and medicine that seeks to celebrate and retain the traditional and humanistic aspects of medicine and healthcare while also embracing the unparalleled opportunities of contemporary science and technology to improve health outcomes and relieve suffering. Two particular interests are the introduction of technology-based innovations in healthcare and

the complex links (philosophical and empirical) between research, policy, and practice. She is the author of 220 peer-reviewed publications and 8 textbooks.

Professor Anne Hudson Jones PhD (b. 1944) received her BA in French (1965) from Louisiana State University and her PhD in Comparative Literature (1974) from the University of North Carolina. From 1973 to 1978, she was Instructor and then Assistant Professor of English at Virginia Tech, where she helped establish an interdisciplinary humanities programme and became Assistant Director of the Center for Programs in the Humanities. In 1979, she joined the Institute for the Medical Humanities, University of Texas Medical Branch (UTMB) at Galveston, to develop courses and research in literature and medicine. A founding editor of *Literature and Medicine* (1982), she was its Editor-in-chief (1983–1994) and has been a Senior Consulting Editor since 1995. At UTMB, where she is now Professor and Harris L. Kempner Chair in the Humanities in Medicine, she helped develop the first interdisciplinary medical humanities graduate programme in the USA (1988) and served as its Director for eight years (2004–2011). She has published widely in literature and medicine

and medical humanities, including two books, *Images of Nurses* (Hudson Jones (ed.) (1988)) and, with Faith McLellan, *Ethical Issues in Biomedical Publication* (Hudson Jones and McLellan (eds) (2000)). She has received many awards, including the John P. McGovern Award from the American Osler Society (1993), the Nicholas E. Davies Memorial Scholar Award from the American College of Physicians (2003), and the University of Texas Regents Outstanding Teaching Award (2013).

Professor Brian Hurwitz
MA MSc MD MBBS FRCP
FRCGP (b. 1951) is a clinical academic who worked as an NHS GP for 30 years. Since 2002 he's been Professor of Medicine and the Arts at King's College London, where he directs the Centre for the Humanities and Health, which is funded by the Wellcome Trust (see <http://www.kcl.ac.uk/innovation/groups/chh/index.aspx>, visited 3 September 2014), and hosts MSc, PhD, and postdoctoral programmes. Based in the Department of English at King's, his research interests include narrative studies in relation to medical practice, ethics, law, and the literary shape of eighteenth to twentieth century clinical case reports. He has co-authored

and edited 140 peer-reviewed papers, 40 book chapters, and several books, including: *Clinical Guidelines and the Law* (Hurwitz (1998)); *Narrative Based Medicine* (Greenhalgh and Hurwitz (eds) (1998)) translated into Italian, German, and Japanese editions); *Narrative Research in Health and Illness* (Hurwitz, Greenhalgh and Skultans (2004)) translated into Japanese; *Health Care Errors and Patient Safety* (Hurwitz and Sheikh (2009)); and *Discourses and Narrations in the Biosciences* (Spinozzi and Hurwitz (2011)). He holds honorary professorships in the Centre for Value, Ethics, Law and Medicine at the Faculty of Medicine, University of Sydney; the Schools of Humanities and Medicine at Hong Kong University; and at the Institute of Neurology, Queen Square, University College London. Prior to his current position he was Professor of Primary Health and General Practice at Imperial College London.

Dr Craig Irvine
PhD (b. 1958) completed his doctorate at Pennsylvania State University in 1993. He has been Director of Education, of the Program in Narrative Medicine at Columbia University College of Physicians and Surgeons since 2002, designing and

teaching cultural competency, ethics, narrative medicine, and humanities and medicine curricula for residents, medical students, physicians, nurses, social workers, chaplains, dentists, and other health professionals. In 2010, Dr Irvine was appointed Director of Columbia University's Master's Program in Narrative Medicine. He has over 20 years of experience researching the history of philosophy, phenomenology, and narrative ethics, and over 25 years of experience teaching ethics, humanities, the history of philosophy, logic, and narrative medicine at the graduate, undergraduate, and preparatory school levels. He has published articles in the areas of ethics, residency education, and literature and medicine, and has presented at numerous national and international conferences on these and other topics.

Dr Elisabeth Kübler-Ross MD (1926–2004) studied medicine at the University of Zürich, graduating in 1957. She moved to America where she trained and worked as a psychiatrist at Long Island's Glen Cove Community Hospital, Manhattan State Hospital, and Montefiore Hospital in New York. She subsequently worked at the University of Colorado School of

Medicine (1962–1965), Denver. In 1965 she became Assistant Professor of Psychiatry at Billings Hospital, Chicago, where her work with terminally ill patients developed. Her influential book, which presented her 'five-stage' theory, *On Death and Dying*, was published in 1969 and was instrumental in the foundation of the modern hospice movement. She wrote several, popular, books on the topics of dying and terminal illness during the 1970s, 1980s, and 1990s. Her final book, *On Grief and Grieving*, was published posthumously (Kübler-Ross (2005)).

Dr John Launer MA MA MB BS MRCP (b. 1949) is a GP, family therapist, educator, and writer. He is Associate Dean for Faculty Development for Health Education England (London), an Honorary Consultant at the Tavistock Clinic, and an Honorary Senior Lecturer at Queen Mary University of London. He has written and co-edited six books, including *Narrative-based Primary Care* (Launer (2002)) and *Clinical Uncertainty in Primary Care* (Sommers and Launer (2013)). Together with Caroline Lindsey he has developed a model of narrative based consultation skills and clinical supervision called 'Conversations Inviting Change'.

He has facilitated workshops on this model of consultation around the world, including in Japan, the United States, and Australia.

Professor Jane Macnaughton
PhD MA MBChB MRCP
DRCOG (b. 1960) is Professor of Medical Humanities at Durham University in the UK and Co-director of the University's Centre for Medical Humanities. The Centre was established in 2008 as a Wellcome Trust-funded development from the Centre for Arts and Humanities in Health and Medicine, which she initiated in 2000. She became Deputy Head of the School of Medicine and Health in 2009. She has published in the fields of medical education, medical humanities, literature and medicine, history of medicine, and healthcare environments. Recently her work has turned to engagement in critical public health, especially in the field of smoking research. This has led to an interest in the phenomenology of breathing and work with clinicians on chronic obstructive pulmonary disease. Her books include *Clinical Judgement* (Downie, Macnaughton and Randall (2000)); *Madness and Creativity in Literature and Culture* (Saunders and Macnaughton (2005)), and *The Body and the Arts* (Saunders, Maude and Macnaughton (2009)). She is also

a founder member of the UK's Association for Medical Humanities and was joint editor of the journal *Medical Humanities* until 2008, and is part of an international publishing collaboration working on a series of medical humanities 'companions'. Her current clinical work is in gynaecology and she is an Honorary Consultant in Obstetrics and Gynaecology at the University Hospital of North Durham.

Professor Kathryn Montgomery
PhD (b. 1939) received a BA (1960) from Newcomb College of Tulane University, an MA in English Literature (1962) from the University of California, Berkeley, and her PhD (1968) from Emory University with a dissertation on the epic satires of John Dryden. She taught at Morehouse College, Atlanta, from 1964 to 1980 and in the late 1970s took part in the creation of the new medical school there. At the University of Rochester School of Medicine and Dentistry she headed its new Division of the Medical Humanities (1980–1988), and in 1988 moved to Northwestern University's Feinberg School of Medicine, where she directed the Medical Humanities and Bioethics Program until 2009. She retired as the Julia and David Uihlein Professor Emerita of Medical

Humanities and Bioethics and Professor Emerita of Medicine in 2013. Montgomery is the recipient of grants and fellowships from the Woodrow Wilson Foundation, the National Endowment for the Humanities, the American Philosophical Society, the National Science Foundation, and the American Council of Learned Societies. She is the author of *Doctors' Stories* (Montgomery Hunter (1991)) and *How Doctors Think* (Montgomery (2005)). In 2001 to 2002 she served as President of the American Society for Bioethics and Humanities and is currently a member of the Fellows Council of the Hastings Center.

Professor Maura Spiegel
MPhil PhD (b. 1954) has a joint appointment at Columbia University and Barnard College where she teaches literature, film, and American Studies. Associate Director of the Program for Narrative Medicine at Columbia College of Physicians and Surgeons, she teaches film to second-year medical students, as well as graduate students in the MS Program in Narrative Medicine at Columbia. She has lectured on film in Venice, London, Dublin, Buenos Aires, Toronto, and in cities around the USA. She co-authored *The Grim Reader* (Spiegel and Tristman (1997)), and *The Breast*

Book (Spiegel and Sebesta (2002)), which was a Book-of-the-Month Club-Quality Paperbacks selection. With Rita Charon, she co-edited the journal *Literature and Medicine* (Johns Hopkins University Press) for seven years. She has written for *The New York Times* and *Newsday*, and has published articles and essays on many topics. She is currently writing a book on the life of Sidney Lumet (St Martin's Press).

Professor Tilli Tansey
OBE PhD PhD DSc HonFRCP FMedSci (b. 1953) graduated in zoology from the University of Sheffield in 1974, and obtained her PhD in *Octopus* neurochemistry in 1978. She worked as a neuroscientist in the Stazione Zoologica Naples, the Marine Laboratory in Plymouth, the MRC Brain Metabolism Unit, Edinburgh, and was a Multiple Sclerosis Society Research Fellow at St Thomas' Hospital, London (1983–1986). After a short sabbatical break at the Wellcome Institute for the History of Medicine (WIHM), she took a second PhD in medical history on the career of Sir Henry Dale, and became a member of the academic staff of the WIHM, later the Wellcome Trust Centre for the History of Medicine at UCL. She became Professor of the History of Modern Medical Sciences at UCL in 2007 and moved to

Queen Mary, University of London (QMUL), with the same title, in 2010. With the late Sir Christopher Booth she created the History of Twentieth Century Medicine Group in the early 1990s, now the History of Modern Biomedicine Research Group at QMUL.

Professor Joanne Trautmann Banks PhD (1941–2007) was the first Professor of Literature at a medical school in the USA when she was appointed to Pennsylvania State University College of Medicine, Hershey, in 1972. She was a co-founder of the journal *Literature*

and Medicine in 1982. She was also a renowned scholar of Virginia Woolf's letters (Nicolson and Trautmann (eds) (1975–1980)). In 1986 she moved to the University of Richmond, Virginia, and subsequently to Eckerd College in Florida. In 2004 she knew that she was terminally ill with ovarian cancer, and gave her last public talk. Her publications include *Healing Arts in Dialogue* (Trautmann (ed.) (1981)); *Literature and Medicine* (Trautmann Banks and Pollard (1982)).

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* Please note that references with four or more authors are cited using the first three names followed by 'et al.'. References with 'et al.' are organized in chronological order, not by second author, so as to be easily identifiable from the footnotes.

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