

THE ROOTS AND RAMIFICATIONS OF NARRATIVE IN MODERN MEDICINE

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‘It is not by chance or by mistake that we commonly speak of stories that happen to us or of stories in which we are caught up, or simply of the story of a life.’¹

Paul Ricœur, 1991

‘Throughout history people have interpreted the world around them and passed on lessons learned through myths, fairy tales, parables, and anecdotes. Medicine is no different, and most physicians can describe the first patient they saw with a particular condition more easily than they can recall the latest research paper in their field’.²

Phillipa Berman and Richard Horton, 2015

Introduction

NARRATIVE BECAME A concept of great versatility and fluidity in the second half of the twentieth century, configuring multi-dimensional understandings and meanings in healthcare. The literary and social theorist Martin Kreiswirth speaks of ‘a massive and unprecedented eruption of interest in narrative and in theorizing about narrative’ in the period,³ which resulted in stories and fragments of stories gaining significant conceptual traction in many discourses and practices. Not until narrative began to be credited with such multi-disciplinary capacities were claims for a pluripotential role in medicine explicitly formulated.⁴

Yet in attempting to respond to human needs incarnated in language, narrativity and medicine have long been co-implicated. If ‘the chief characteristic of human life is that it is always full of events which ultimately can be told as a story,’⁵ as Hannah Arendt argued, narrativity is a precondition of epitomising and reflecting on illness.⁶ Lauren Kassell in this volume finds cases and cures in clinical casebooks of the early modern period redolent of life stories and draws attention to historical work that has delineated how intertwined knowledge and narratives were in the medical *observationes*, *historia* and *exempla* of the period.⁷ Later accounts of disease evolved in various storied formats in relation to a wider culture of narrative forms,⁸ and medical students

today devise their own narrative strategies to organise clinical information, espouse healthcare roles, and assimilate the emotional content of their studies.⁹ It is therefore not surprising that in 2015 the editors of *The Lancet* announced their decision to devote more publishing space to case reports in the distinctively narrative terms of the second epigraph to this chapter.¹⁰

We will trace the shifting place of narrative and narrative theorising within biomedicine, and in considering clinical cases, patients' stories and illness narratives, the focus will not only be on texts but also on practices, conversations and activities, narrations which relay lived experiences and identities in the making in narrative terms.¹¹ Following Roger Smith's explication, we use story and narrative almost interchangeably 'as the older word "history" with a lost syllable, while the German "Geschichte", the Russian "istoria" and the French "histoire" all denote both history and story.'¹² We take narrative to be the umbrella term for these *storia* and argue for their continuing valency in both medicine and 'the emergent discipline'¹³ of the medical humanities.

Lived Experience and Medical Narratives

In *The Illness Narratives* (1988), a study that helped shape thinking in the medical humanities, Arthur Kleinman centres storytelling on the experiencing subject and on a criss-cross of disciplines. Drawing on the notion of illness as a 'biographical disruption',¹⁴ Kleinman focuses on repeated attempts at sense-making in response to suffering:

The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering. The plot lines, core metaphors, and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging experiences in meaningful ways and for effectively communicating those meanings.¹⁵

Expressive self-presentations and self-representations are narrative and reparative processes that offer diagnostic, therapeutic and interpersonal opportunities for helping people cope with illness and trauma, but their potential, Kleinman argues, cannot be fully realised without greater disciplinary porosity in medical research and practice: 'Until anthropological, sociological, psychological, historical, ethical, and literary studies (the human sciences of medicine) become a substantial division of medical research, we will lack the knowledge needed to more systematically conceptualise illness experience and meanings.'¹⁶

Although eighteenth- and nineteenth-century epistolary practice could involve prolonged correspondence, 'self-anatomies' of nervous and physical complaints that profoundly disrupted the daily lives of sufferers, book-length personal accounts in which illness plays a conspicuous part begin to appear in a concerted way only in the second half of the twentieth century.¹⁷ Today, such accounts encompass fictional and non-fictional stories of ill health,¹⁸ poetry, drama, newspaper columns, films and online fora devoted to disease and injury, alterations in mood and sense of self,¹⁹ and feelings for 'selfhood beyond the human',²⁰ which David Herman discusses in this volume in relation to autism.²¹

The sociologist Arthur Frank recognises that such ‘telling does not come easy’.²² The sick are wounded not only in body but often also in voice, and Frank is all too aware of the commotions that a breakdown in health causes: ‘Caregivers are confronted not with an ordered sequence of illness experiences, but with a stew of panic, uncertainty, fear, denial, and disorientation.’²³ Like Kleinman, he finds recounting illness reparative in generating new perspectives on the visceralities of illness and interrelationships of body, self and social functioning that sufferers may previously have taken for granted, and which severe illness disrupts. Recounting reorients, and whilst Frank distinguishes the narrative of an illness from the illness itself, he also recognises that such accounts frequently stand in for the experiential flux of ill health.²⁴ To chart the experiences of painful illnesses and injuries over the past two and a half centuries, the historian Joanna Bourke turned to letters, memoirs, poems, prayers, songs, stories, images, textbooks, music and philosophical and scientific papers.²⁵ Today pain is also expressed in films and television dramas, blogs, YouTube videos, graphic novels and social media, the form and content of which attract the attention of medical humanities scholars.

Narrative Forms and Structures in Medicine

At its core, narrative ‘makes no commitment to truth or falsity, to a real or merely imaginary subject matter . . . [b]ut it does bear a commitment to connectedness and to structure’, argues the philosopher Peter Lamarque,²⁶ properties medicine valorises in the construction of clinical cases. Cases unfold over time as a species of historical account, a type of explanation that the philosopher Louis Mink characterised as ‘grasping together . . . understanding which consists in thinking together in a single act . . . the complicated relationships of parts . . . experienced only *seriatim*’, a type of explanation that binds different elements together, conferring on the ensemble an order of significance.²⁷

Although the notion of a clinical case as an entity is clearly discernible in the Hippocratic era,²⁸ the historians of science, Volker Hess and Andrew Mendelsohn, argue that case reports attain their modern form as authoritative accounts only in the eighteenth century, when cases begin to be written about as more or less free-standing ‘collections of observable data’ linked to specific individuals.²⁹ Prior to this period, case materials were much more diffusely embedded and distributed in texts than they are today. Clinical casebooks and compendia mingled elements from earlier with those of later observations, the patient’s medical history being recounted in terms of precepts and doctrines that did not necessarily distinguish between first- and second-hand observations and commentary.³⁰ Only when such compendia were made accessible through indexing, which required rearrangement of contents according to keywords, did the details of similar types of case come to be clustered together, making possible comparisons between cases isolable from each other and from background information.³¹

Building on links between news and narrative, eighteenth-century case reports began to be published as free-standing accounts of medical findings, instances of special interest titled ‘a narrative’³² sometimes written in tones referencing an account

of a life.³³ Peter Logan's work on hysteria in the late eighteenth and early nineteenth centuries demonstrated the 'intricate association between medical theory and narrative form',³⁴ and supported Thomas Laqueur's identification of a new literary aesthetic in the period, which brought together literary and scientific writings in a 'new humanitarian narrative'³⁵ licensing memoirists and novelists to focus on the intimate details of a life, to elicit compassionate responses from readers made witnesses to corporeal scenes previously confined to autopsy reports and case histories.³⁶

A range of social, political, cultural and medical developments accompanied these changes, which began to challenge the value of narratively organised case reports. The invention of medical instruments yielded information novel to clinical texts grounded in traditional templates – diaries, commonplaces and testimonials – including sounds heard through the stethoscope, interior appearances made visible by the ophthalmoscope, and temperature levels read off the thermometer.³⁷ Hess and Mendelsohn chart the ways in which medical texts began to tabulate and graph information along new dimensions and axes, 'from particular narratives to a general narrative – from histories of patients to the general . . . history . . . [which] required passing through the non-narrative form of the table [of data]'.³⁸ New terminology arose that renarrativised the language of case reports, featuring concepts no longer rooted in patients' own accounts of ill-health experience, and instead focused attention on signs rather than symptoms, on body parts rather than humours or temperaments, on diseases rather than people, and on data rather than sick individuals.³⁹

Clinical encounters incorporated a new language of observation and measurement, and sought – not always successfully – to reduce uncertainty by decentering the place of the verbal story in clinical work.⁴⁰ But rather than removing stories altogether from medical settings, changes in the contents of case description shifted their meaning, and in the twentieth century older narrative forms came to be reassessed. Attempts to understand the psychological and social dimensions of illness, to value patients' views as part of a wider interest in recovering marginal voices, re-emerged in fields such as social medicine and medical ethics; and after the founding of patient organisations and subsequent appearance of consumer health movements, the patient and their account (rather than solely the disease, disease technologies and the medical case) regained the centre of attention.⁴¹

To begin with, this shift was not understood in narratological terms. Two of the most important mid-twentieth-century thinkers, Michael and Enid Balint, worked with London general practitioners to encourage psychoanalytically informed discussion of doctor–patient relationships. *The Doctor, His Patient and the Illness* (1957), their first account of such groups, sought to frame the clinical work of general practitioners in dialogue and preparedness to examine the emotional dynamics of consultations through sustained focus on case stories.⁴² Accounts by patients also came to attention in quite different settings, in studies which reported that three-quarters of people referred to hospital outpatient facilities could be diagnosed by careful attention to the history recounted in the clinic, the results of examination and investigation being far less contributory.⁴³ Such findings bolstered Hermann Blumgart's mid-century injunction, announced in the pages of the *New England Journal of Medicine*, to 'Listen to the patient's story – he is

telling you the diagnosis,' a call intended to shore up the position of history-taking in the clinic, then threatened by over-reliance on medical investigations.⁴⁴

The nature of medical consultations also became a focus of study as part of the growing interest in everyday discourses. William Labov and Joshua Waletzky, sociolinguists of the 1960s, studied verbal accounts of personal experience,⁴⁵ matched clauses of story talk with events and situations, and started to speak of 'narratives of personal experience'.⁴⁶ The social psychologist, Elliot Mishler, and medical educators, Patrick Byrne and Barrie Long, adopted similar methods to study sequences of talk and pause in clinical settings.⁴⁷ They found hospital clinics to be sites of linguistic juncture: interruptions of patients attempting 'to say more than . . . asked for often in the form of stories',⁴⁸ fragmented listening to people with different world views, and patients, carers and doctors seemingly locked in asymmetrical relationships that 'placed the doctor on top'.⁴⁹

Oliver Sacks found himself on the receiving end of such half-listening attention following a severe leg injury, about which he wrote a memoir, *A Leg to Stand On* (1984). Already well known for *Migraine: The Evolution of a Common Disorder* (1973) and *Awakenings* (1973),⁵⁰ both of which featured extended clinical cases, Sacks had been influenced by the writings of the nineteenth-century physician, Edward Liveing⁵¹ and the Russian neuropsychologist, Aleksandr Luria.⁵² He had found Luria's clinical cases so redolent of 'pathos, poignancy and drama' that on first reading them he believed he was immersed in biographies, later calling them 'non-fiction novels'.⁵³ In *Awakenings*, Sacks sought to develop 'clinical tales' that would evoke 'the real and full presence of the patients themselves, the 'feeling' of their lives, their characters, their illnesses, their responses – the essential qualities of their strange situation', and to actualise through 'narrative and reflection . . . proliferation of images and metaphors . . . remarks, repetitions, asides, and footnotes . . . the landscapes of being in which these patients reside'.⁵⁴

Sacks's memoir of his broken leg focused on loss of proprioception in the injured limb and his profound alienation from it, which involved a breakdown of memory, thinking and will: 'not just a lesion in my muscle but *a lesion in me*',⁵⁵ he explained. In keeping with previous works, Sacks's account of the effects of his injury evoked a 'landscape of altered being' that transcended the repeated assertions of his hospital attendants that nothing other than damage to his leg muscle and bone was the matter with him. Sacks was able to take sufficient account of his lived experience to deconstruct his medical training and thinking, and challenge the constraints and limitations of conventional case descriptions.⁵⁶ In the preface to the book he argued that:

the case as a genre is a form of natural history . . . [that] tell[s] us nothing about the individual and his history; . . . nothing of the person, and the experience of the person, as he faces, and struggles to survive his disease. There is no 'subject' in a narrow case history; . . . To restore the human subject as the center – the suffering, afflicted, fighting, human subject – we must deepen a case history to a narrative or tale; only then do we have a 'who' as well as a 'what', a real person, a patient, in relation to disease.⁵⁷

Blurring the boundary between clinical case reports and memoirs, Sacks's tales offered portraits of the ill in the midst of their disease. Not only was he able to develop 'thick descriptions' of people in sufficient, situated detail to ground medical judgements about them,⁵⁸ he also brought a moral and aesthetic responsiveness to bear on how to understand the people for whom he was responsible, both clinically and in his writing about them in ways more familiar to life-writing and literary narrative than to the genre of the case report.⁵⁹

The Development of Narrative Methods in Modern Medicine

The application of narrative theory to patients' verbal 'stories' and 'histories' in the clinic is a relatively recent form of narrative method, and by no means the only one of significance for medical practice. In the late twentieth century, interest in the relationship between medicine, health and narrative centred on studies in the social sciences (understanding how people frame and understand health and illness), and on literature and medicine (representations of health and illness within medicine and culture). Sociological fieldwork offered ethnographic frameworks and models for understanding narrative processes operative in many healthcare practices. In the 1990s, for example, Paul Atkinson, who would later be critical of the ways in which narrative came to be deployed in healthcare research,⁶⁰ found stories an apt way to characterise medical enactments: 'I have been struck by the need to preserve the form of the talk and interaction . . . narratives and arguments which are not captured adequately by the accumulation of short gobbets of talk,' he wrote.⁶¹ Introducing an ethnographic study of haematology services in the UK and USA, he reworked his field notes, reporting that he had

become preoccupied with aspects of the rhetoric of medical work and medical instruction . . . rhetorical devices used to construct and convey the cases that provided the basis for so much medical discussion. On re-reading my own field data I was forcibly struck – as I had not been when I first analysed them – by the presence of various narrative and descriptive methods that had been used by clinicians to generate and reproduce medical knowledge . . . instances where surgeons artfully created stories about patients and their conditions . . . akin to mysteries or cliff-hangers, sometimes morality tales of success and failure . . . One could start to think in terms of an ethnopoetics of medical work.⁶²

Here we see narratives undertaking more than a configuring or figuring-out role: as components of an 'ethnopoetics', they express aesthetic and affective aspects of medical understanding. The philosopher David Velleman likens the beginning of a story to 'an itch that demands scratching', the middle sections 'postponement of the stimulus reduction by obstacles and misdirected efforts . . . and the end . . . the satisfying discharge that pacifies, if only temporarily.'⁶³ The suspenseful dramas Atkinson saw enacted in case presentations choreograph cadences of arousal and resolution together with medical understanding as instances of 'fit' between clinical work and narrative types familiar to other cultural domains.⁶⁴

Medical education developed some of the first practical responses to interest in the inter-relationships between cases, patients' stories and illness narratives, particularly in the US. It was in this context that literature and medicine came to be a particular focus of medical engagement, both with fictional accounts of illness and real-life illness narratives. Although these initiatives developed unevenly, one study estimated that, by 1994, approximately a third of US medical schools employed faculty in the field of literature and medicine.⁶⁵ Many courses focused on close reading, often in the service of a practical outcome of clinical care, rather than on engagement with narrative theory.⁶⁶ Others moved away from literature to engage with narrative as part of a multi-disciplinary clinical method, albeit with the focus still on instrumental value, which limited the degree to which medical education could grapple with the complexities of narrative form and literary theory. In an interview, Kathryn Montgomery has observed that US medical education promoted

skills that can be described as hermeneutic; the skills of interpretation, making sense of things – all very valuable for future clinicians. 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 situated for practical, clinical students.⁶⁷

Even before the emergence of narrative medicine as a nameable entity, patients' stories were becoming increasingly central to medical contexts. While many contexts demanded an instrumental view of the patient's account, servicing improved doctor-patient relations and better diagnosis, others supported looking beyond biological and diagnostic tools towards methods that opened up personal space and emotional exploration in clinical encounters based on richer clinical dialogues.⁶⁸ Rita Charon coined the term narrative medicine to refer to

medicine practiced with the narrative skills of recognising, absorbing, interpreting, and being moved by the stories of illness Along with their scientific expertise, doctors need the expertise to listen to their patients, to understand as best they can the ordeals of illness, to honour the meanings of their patients' narratives of illness, and to be moved by what they behold so that they can act on their patients' behalf.⁶⁹

The approach she articulated in *Narrative Medicine: Honoring the Stories of Illness* (2006) is predicated on a multi-modal and polymorphous notion of narrative:

As a living thing, narrative has many dimensions and powers. The novelist values its creative force; the historian relies on its ordering impulses, the autobiographer redeems its link to identity . . . Narrative structures, such as novels, newspaper articles, and letters to friends, enable us to recount events, to depict characters, to suggest causes for events, to represent the passage of time, to use metaphor to convey meanings otherwise elusive. As an instrument for self-knowledge and communion, narrative is irreplaceable.⁷⁰

Where Drew Leder had earlier called for a nuanced hermeneutics that would recognise multiple healthcare texts – the patient’s experience, the doctor’s interpretation of the ‘problem’, a ‘reading’ of bodily signs, and ‘instrumental texts’ arising from technological investigations⁷¹ – Charon emphasises the critical role of ‘narrative competence’ in clinical medicine, drawing on performance,⁷² discourse⁷³ and human cognitive processes.⁷⁴ Her advocacy implies not simply the *use* of narrative but a practice ‘fortified’ by ‘the capacity to recognize, absorb, metabolize, interpret, and be moved by stories of illness’.⁷⁵ Whether such a competence can be fully characterised and made operational, or is as much a philosophy of healthcare practice as it is a set of specifiable skills that cohere, the notion of fortifying practice with a bricolage of narrative methods, in place of narrative being the handmaiden to better diagnosis, opens up new roles for narrative awareness in clinical settings.⁷⁶ Charon’s narrative competence ‘honor[s] the meanings’ (in the multiple) of illness, and is achieved by making writing and reading, and narratological understanding integral components of clinical method. To honour meaning in this way requires accurate listening, soliciting and precisely representing what is going on in a clinical situation, and the ability on the part of the clinician to manage the emotional and perspectival changes emerging from entering into and stepping out of healthcare scenarios.⁷⁷ In Charon’s account, this responsiveness is engendered through learning to read – hear, observe, self-observe and interpret – to write and depict clinical situations in new ways.

When doctors or nurses listen to patients in this way, related to what psychiatrists call ‘listening with the third ear,’ they will ask themselves readerly questions: ‘Why is she telling me this now? Why do I feel irritated or distracted or sad as I listen to her? Why did she start with the end of the story and tell it backwards?’⁷⁸

Underpinning the approach is an ethical stance of accompaniment: devoting enough time to hear fully what patients have to say, however digressive by conventional medical standards this may turn out to be, and becoming a witness to suffering framed as a form of ‘beholding’ that takes in the many aspects of ill health. To gain this capacity, ‘[t]raining is textual and interior,’⁷⁹ she writes, and grounded in enlarging clinicians’ absorptive capacities, reflective discernment and self-knowledge.⁸⁰

This programme – sometimes referred to as the ‘Narrative Medicine movement’⁸¹ – is predicated on reading and writing practices that promote a simultaneity of thinking and feeling that clinical work often seems to distract apart.⁸² For the writer and clinician Terry Holt, the principal way in which skills honed through textual engagement apply to clinical practice is through self-observation and reflection, which grants practitioners ‘the strength, the right – and the obligation – to give people care’.⁸³ For Holt, self-observation supports responding to and ‘*experiencing*’ and ‘*analyzing*’ that response, ‘tracking it to its sources in narrative convention, in language, in culture and psychology’.⁸⁴ This is a vision of clinical work anchored in reflectiveness translated into a healthcare attentiveness that strengthens the capacity of practitioners ‘to look beyond the biological mechanisms at the centre of conventional approaches to medical practice, towards domains of thought and ways of telling that focus on language and

representation, on the emotions and relationships'.⁸⁵ Such narrative-based practices recognise that people who are ill or think themselves ill locate concerns and symptoms – often disjointedly – in interpersonal and social networks of meaning that are in differing stages of formation.⁸⁶ It is an approach that does not dispense with scientific medicine but recognises the place of narratives in science; the challenge becomes how best to deploy narratives contextually in ways attuned to the needs of individuals.⁸⁷ In some clinical circumstances, purely biomedical responses may remain appropriate, writes John Launer, the author of *Narrative-based Primary Care* (2006):

If a patient asks 'is this a bunion and do I need an operation?', the best way to reply may sometimes simply be 'yes'. However . . . [a]n opening story that seems brief and fragmentary is more likely to be the prologue to a far more elaborate one, steeped in personal meaning . . . 'I slept really badly last night because I was so worried about my job interview, then on my way to the interview I was so distracted that I tripped over my bad toe, was in agony, made a mess of the interview, my husband is furious because we need the money.'⁸⁸

In this snippet of a report a question elicits a straightforward response, but it begins to be reconsidered as the context and significance of the woman's failure at her job interview comes into view. The account of the consultation takes on a semi-biographical aspect, medical attention moving to personal and interpersonal terrains, where the bunion – the entrée to consulting – may (or may not) be the central issue. It is possible to imagine the discussion delving further into financial matters, previous job interviews, and the sort of work the patient is looking for. Should the bunion be identified as the main concern, or is it anxiety, poor sleeping, her capacity to become distracted (and trip over) or something else that is the central issue to consider?

In narrative-based practice the drive is to make sense of the events in question, whether (and how) they may be connected, and which elements may be paramount. The approach is quite a long way from reading texts, literary or otherwise, its consideration being conversational and ethnographic in stance and psychological in feel. Launer's approach aims to understand clinical work through detailed conversational reconstruction, for which careful account needs to be taken of how everyday narratives are put together and interactionally framed and told. Building on Howard Brody's appeal for medical accounts to be co-constructed with patients,⁸⁹ Launer promotes '*collaborative attempts to agree on a useful and coherent story*', which he terms narrative inquiry.⁹⁰ His is a notion of storied investigation that encompasses descriptions and conversations of situations people are caught up in, the aim being to test out whether stories can be agreed that help resituate patients in networks of meaning that offer more hopeful opportunities.

Fallout and Future of Narrative in Medicine

In tracing the roots and ramifications of narrative in relation to healthcare, we have not adopted an all-encompassing definition or even a minimum set of conditions for

what counts as a story. We have noted the way in which the terms have been used in relation to medical discourse and have mapped their invocations in different contexts, most dominantly perhaps in reference to the patient's account of a complaint, the medical history, and its reconstruction in a clinical account of a case. Cases are not generally accounts of illness as felt and lived from within, although they frequently include snippets of first-person accounts deriving from the patient's medical history. Standardly, case reports are terse outsider views of a person's situation recounted from a distinctively medical or psychiatric standpoint, rendered in detached, depersonified and factual terms, Sacks's clinical tales revealing the uneasy tension that subsists between cases embodying a highly medical(ised) account of a patient's situation and those cast in terms of a life story.

More recently, story and narrative have referenced conversations and interactions between patient, carer and health practitioner. However haltingly told, the patient's story for Frank stands outside this nexus: it is not an account in thrall to the values, categories or interview procedures of modern medicine.⁹¹ Rather, it is a reflection 'on body, self, and the destination that life's map leads to',⁹² precipitated by ill health, an act that undertakes autobiographical work that may involve coming to terms with loss and mourning, altered capabilities and social functioning. In writing his own memoir of a heart attack and cancer, Frank found himself writing 'for the times I had to remain silent and for those who are still silent'. Later editions of *At the Will of the Body* (1991) include an afterword, in which he acknowledges the many letters he received when the book first appeared, thanking him for putting into words aspects of others' experiences. The passivity that so frequently accompanies severe illness is made all the more profound as a result of the language to which patienthood is subjected by modern healthcare, which has been colonised by objectivist interests and concepts that threaten to eclipse the communal language of the lifeworld, the everyday concerns of bodily and psychic experience.

Patient organisations today call for accounts of the everyday world of illness experience to help forge a shared culture and identity for their membership.⁹³ Some fora express resistance to medical discourse, attracting contributions from people who feel misunderstood by the mainstream health service, who seek to reformulate their experience and commission new research that can generate alternative understandings of their problems. Social and commercial entrepreneurs have additional reasons for searching out healthcare and illness experiences. Healthtalk.org, a database of patient experience created through a partnership between a charity and a health services research group in Oxford, garners patient stories for research and educative purposes, in order to further recognition of medical conditions, care pathways, symptom patterns, patient and carer expectations, and treatment options. Employing a suite of qualitative and life-story methods, Healthtalk.org collects information by interview of representative samples of people with medical conditions, which it arranges thematically and posts online as organised transcripts and audiovisual clips, its research generating grounded knowledge of patient experience useful to public and professionals alike, and published in peer-reviewed journals.⁹⁴

PatientsLikeMe, a Boston-based for-profit company ‘but not one with a “just for profit” mission’, provides a disease-focused, social research platform for patients to ‘share and learn from real-world, outcome-based health data’. It has developed a large following of people wishing to contribute their own accounts of ill health to scientific research and lobby for better healthcare. PatientsLikeMe appeals for patient stories – it especially draws interest from people with rare conditions – from which it extracts and validates data that bear on specific questions, and in this way, for example, has examined whether taking the unlicensed drug lithium carbonate can alter the deteriorating course of amyotrophic lateral sclerosis.⁹⁵

These organisations appeal to the rhetoric of stories to garner ill-health experiences, but in the case of PatientsLikeMe the drive is to extract data for research that retain little of the voices of participants – upset, anger, protest – or of their individual stories. The data are processed with the needs and claims of members in mind, but the assumptions and methods employed denarrativise the contents and it is unclear how the originating stories are valued in their entirety and on their own terms. By contrast, although the approach of Healthtalk.org risks cutting across aspects of the stories it works with – extracting and highlighting certain themes and ignoring other elements may annul an account’s internal relatedness – many of its outputs retain the voice, mood and some of the narrativity of the collected materials.⁹⁶

Both these initiatives hardly register the uneasy relationship between patient voice and mainstream medicine highlighted by Frank. Yet, in different ways, Healthtalk.org and PatientsLikeMe empower patients and carers. So, too, do online organisations that collect patient and carer voices for more consumer-oriented purposes: to convey the gist of their experiences to relevant healthcare staff, add them to user service ratings, and make the amalgamated information more widely available. Some sites offer patient-held medical records and access to e-networks, promising ‘true patient-centred care’; one organisation appeals to people to ‘Tell your story . . . [and] make a difference by sharing your story with us and we’ll make sure your story reaches the right person.’⁹⁷ This call appears on a website that has collected over 110,000 accounts. The site has become a repository of conversational and epistolary interactions about what has happened to patients in reference to healthcare norms, standards of care, patient safety, waiting times, the courtesy and caring qualities of healthcare staff, and hopes for more responsive health services. The data are arranged by encounters in named facilities, where story colloquially and elastically stands not only for the personal and the human in modern healthcare but also for a rebalancing of power in patient–professional relations in favour of patient-consumers. The format of story entry is managed by headings such as: ‘What is your story about?’, ‘What happened?’ and ‘What conditions, tests and treatments are in your story?’, and provides testimonies UK health-service managers find helpful in commissioning health services.⁹⁸

There is little sign that these accounts are valued beyond the *what* that they report, as opposed to *how* they knit experience together,⁹⁹ a distinction critical to understanding why stories work *for* people and *on* people.¹⁰⁰ They appear to be almost entirely data-driven vehicles solicited for very particular purposes that cut

across Frank's proposal for a 'sociology of witness'¹⁰¹ and the foundational position developed in *The Wounded Storyteller*, in which he argues that 'people's stories are not "data" to support various propositions that I advance. Instead, the stories are the materials that I use to model theorizing – and living – with stories.'¹⁰²

We have seen that narrative is deployed in many healthcare contexts in variable and loosely patrolled ways, in threads of usage and applicability that predate the explosion of interest in narrative theorising of the second half of the last century. Although it continues to occupy a contested position within the medical humanities, there is little sign of the traction narrative has gained diminishing.¹⁰³ On the contrary, its role is vital, clinically methodological as well as explanatory of complex, variable, time-dependent human circumstances. In recognising the human at the centre of healthcare encounters and posing questions about how these qualities are to be understood and represented, narrative fulfils a critically important symbolic role. Illness narratives repeatedly indicate that medical problems ramify far beyond healthcare,¹⁰⁴ which it is the task of the medical humanities to comprehend and interpret. Despite concern that the rhetorical appeal of narrative may be out of control,¹⁰⁵ disciplines that hold its ordering capacities central to their analysis and commentary recognise how '*narrative* resists straightforward and agreed-upon definitions and conceptualizations',¹⁰⁶ a resistance that acknowledges the multiplicity of roles stories continue to play in human affairs.

Further Reading

- Martin Kreiswirth, 'Merely Telling Stories? Narrative and Knowledge in the Human Sciences', *Poetics Today* 21 (2000), pp. 293–318.
- Peter Lamarque, *The Opacity of Narrative* (London and New York: Rowan & Littlefield, 2014), p. 17.
- Neil Vickers, 'Illness Narrative', in Adam Smyth, *The Cambridge History of Autobiography*, 9th edn (Cambridge: Cambridge University Press, 2016).
- John Harley Warner, 'The Aesthetic Grounding of Modern Medicine', *Bulletin of the History of Medicine* 88 (2013), pp. 1–47.
- John Harley Warner, 'The Uses of Patient Records by Historians – Patterns, Possibilities and Perplexities', *Health and History* 1 (1999), pp. 101–11.

Notes

1. Paul Ricœur, 'Life in Quest of Narrative', in David Wood (ed.), *On Paul Ricœur: Narrative and Interpretation* (London: Routledge, 1991), p. 29.
2. Phillipa Berman and Richard Horton, 'Case Reports in *The Lancet*: A New Narrative', *Lancet* 385 (2015), p. 1277.
3. Martin Kreiswirth, 'Merely Telling Stories? Narrative and Knowledge in the Human Sciences', *Poetics Today* 21 (2000), pp. 293–318.
4. The claim that literature could enhance wider cultural awareness on the part of doctors preceded a specific focus on narrative. Anthony Moore, 'The Art of Medicine: A Missing Subject', *Medical Journal of Australia* 2 (1975), pp. 27–8; Anthony Moore, *The Missing*

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 7. Lauren Kassell, 'Paper Technologies', in this volume, pp. 120–35.
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 13. Claire Charlotte McKechnie, 'Anxieties of Communication: The Limits of Narrative in the Medical Humanities', *Medical Humanities* 10 (2014) <<http://mh.bmj.com/content/early/2014/05/28/medhum-2013-010466.short>> (accessed 28 October 2014).
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24. See Clifford Geertz in Victor W. Turner and Edward M. Bruner (eds), *The Anthropology of Experience* (Urbana and Chicago: University of Illinois Press, 1986), pp. 373–80 (p. 373).
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