Narrative Research in Health and Illness

Edited by

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Introduction

> Narration is as much part of human nature as breath and the circulation of blood.
>
> (As Byatt, 2000)[1]

Narrative studies hail from widely differing territories within the humanities and social sciences,[2] but they share, at their core, both a teller and a tale. Storytelling invokes words uttered and heard or written and read, images depicted and deciphered or gestures enacted and understood. Once closely aligned with the spoken or written word, narrative studies today embrace a wealth of other expressive media, including dance, film, mime, comic strips, song, and painting.

Polymorphous in content, malleable in form and dynamic in expression, narratives are compositions of unfolding meanings which can be discerned and followed by an audience.[3,4,5] Narrative thinking and imagining therefore embody temporal and causal frames of reference manifest in myths, cave art, fables, fiction, and drama. Closely synonymous with humanity itself, narrative capabilities such as imagining, hypothesising and plotting have offered marked evolutionary advantages to humans over thousands of years.[6]

This book takes forward and extends a number of themes set out in *Narrative-based medicine*,[7] an earlier volume published at a time when many practitioners in health care sensed the narrowness of the prevailing rationalist framework in medicine and were beginning to take note of the "narrative turn" in the social sciences and humanities. We were not by any means the first writers to recognise the importance of narrative in clinical practice (see, for example, the earlier major contributions of Balint,[8] Kleinman,[9] Brody,[10,11] Mishler,[12] and Montgomery Hunter).[13] We saw our objective at that time as building a bridge between this somewhat sparse, specialist literature and the practitioner at the bedside who was drawn to the concept of "narrative health care" and was looking for the linguistic and intellectual tools with which to describe and analyse his or her experience.

Seven years on, we were asked to produce a second edition of *Narrative-based medicine* and realised that we needed to do more than ask the chapter authors of the previous book to update their contributions. By this time, narrative in health care was developing its own corpus of research and had a thriving network of scholars drawn variously from the health professions, anthropology, philosophy, and other primary disciplines, who were debating its conceptual, theoretical, and methodological basis, and who came together regularly in conferences, seminars, and the virtual reality of email communities, to present their empirical work and discuss contemporary problems and challenges.

Any new book on the narrative basis of health care, we felt, would need to reflect its new found maturity as a field of interdisciplinary study, should set out its emerging evidence base, and critically explore its methods of enquiry. We have therefore structured the book to reflect the current theoretical and empirical landscape of narrative studies, and in particular to indicate how narratives mediate between subjective and objective points of view and between the personal, institutional, and social dimensions of health and illness. We have also included one or two more radical chapters that question some generally accepted assumptions, expose controversies, and suggest alternative perspectives for future enquiry.

Structure of the book

We have divided the book into three sections, though it should be noted that some chapters straddle the following taxonomic categories. **Section 1: Narratives** includes ten chapters, mostly based on empirical research, that present the voice of the patient, carer or companion. Together they illustrate the range of knowing that is generated by a narrative approach. They demonstrate important differences in the methodology of research that seeks to collect stories from the ill, vulnerable, dying, and bereaved or that seeks to explore the dynamic interactions between teller, tale, and listener. **Section 2: Counter-narratives** addresses the rhetorical, subversive, and creative roles of narrative. The first chapter of this section delineates two contrasting narratives of deafness identity and affiliation, while the following three present a lesser-known story as a challenge to another, more dominant or accepted story. The final chapter in this section shows how new counter-narratives can arise and begin to hold sway despite facing opposition from scientifically based counter-narratives concerning how best to contain a very small risk of a very serious danger eventuating. **Section 3: Meta-narratives** considers the grand narratives of society, history, and ideology within which our individual life stories (as citizens, risk takers, health service users, researchers, scientists, or policy makers) are enacted. The remainder of this introduction sets out some of the key theoretical issues covered in these three sections. It is not necessary to read the introduction in full before sampling the chapters, but you may like to return to this section periodically as you work through the book.

Section 1: Narrative

The need to reconcile the subjectivity and uniqueness of human experience with the physical reality of the body and a larger impersonal picture besets all the human sciences.[14] But it poses a special challenge for clinical practice, perched as it is between the singularity of personal experience and the generalities of biological structure and mechanism.[15] Howard Brody, contributing to the predecessor to this volume, formulated the problem in this way:

> To deal with the part of medicine which treats everyone as the same, we must extract the narrative from the patient and recast it as a "case history" or as a medicalised retelling of the story. If we do not do this we can never bring to the patient the undoubted benefits of modern medical science. If we do only this, we dehumanise the patient, fail to address him or her as an individual, and ultimately may very well increase the patient's suffering.[16]

The philosopher Richard Wollheim, in *The Thread of Life,* unravels subjectivity in terms of viewpoint, arguing that: "the subjectivity of a phenomenon is how the phenomenon is for the subject".[17] Much of Western science has promoted objectivity at the expense of subjectivity – to describe a view as "subjective" has become a way of discrediting that view. Both as individuals and more particularly as scientists, we learn to impose an artificial, impersonal order on the world and to equate that with reality.[i] But as the philosopher Thomas Nagel makes clear in discussing the importance of human experiences, our lives are not lived through the mediation of an external observer: "Life is lived from inside, and issues of significance are significant only if they can be raised from inside"[22] (p 197). "Insideness" cannot therefore be ignored, Nagel argues, for there is something irreducible about subjectivity, which cannot be captured by causal or functional explanations. He illustrates this non-reducibility with the example of the bat: "Even without the benefit of philosophical reflection anyone who has spent some time in an enclosed space with an excited bat knows what it is to encounter a fundamentally alien form of life" (p 168). No amount of understanding of the brain mechanisms of the bat will tell us what it *feels like* to be a bat, or to see the world through bat ears. There is an explanatory gap because any account based on observation and measurement leaves out subjectivity. As Nagel asks, "What would be left of what it was like to be a bat if one removed the viewpoint of the bat?" (p 173).

The chapters in Section 1 illustrate a key contribution of the narrative perspective: the requirement that human subjectivity should no longer be seen as the devalued opposite of scientific objectivity, linked in some assumed zero-sum relationship whereby more of the one must necessarily mean less of the other. Rather, objective assessment (for example, medical diagnosis) and objective intervention (for example, medical treatment or palliation) provide but one important dimension of knowing. However complete the objective dimension, if we exclude subjectivity and its narrative expression through dialogue, we remove diversity of viewpoint and impoverish the knowledge we can gain about human suffering and the impact of our efforts to care.

In Chapter 1 Rita Charon begins the Narrative section by portraying a patient – seen two days before she penned the chapter – who was "profoundly depressed, non-English-speaking, with a discouraging list of ailments including atrial fibrillation [an irregular heart beat] with its attendant need for chronic anticoagulation, and disabling back pain unresponsive to conservative management". The core challenge in the encounter was not to complete the various biomedical checks and decisions (complicated though they were), but to find a way – through the depression, through the language barrier, through the profound social distance that poverty generates – to engage with this woman as one human to another. Once Charon could achieve this, the biomedical encounter became straightforward and the various medical interventions could be efficiently arranged. She comments: "The satisfaction I felt was the satisfaction of an *internist* – not of an ethicist and not of a narratologist although I am those things too – in my having found a way, today anyway, to be her doctor."

The Italian philosopher Cavarero distinguishes two key questions about the nature of human beings: "The first asks 'what is man?' The second asks of someone 'who he or she is'".[23] Who-questions are often superficially collapsed into what-questions because it seems easier to describe oneself in role (as a teacher, parent or Bristolian, for example) than to address the question of who we actually are. To fully address a who-question requires a story to be told about how we have come to be the person we are. Instead, schematic "stick figure" characterisations come to stand in for the narrative of personal identity.[24] But understanding human beings requires more than characterisation, as Goldie makes clear, when considering an actor preparing to play a part[25] (p 198). The actor not only needs to study the script, but to learn also about the biographical and subjective background of the individual he or she is playing.

Clinicians, like their academic colleagues, may feel more at home with characterisation than with narrative. Characterisation ("a housewife", "a drug user", "a social worker") encompasses the shared aspects of experience and the generalisable. Narrative, on the other hand, expresses the uniqueness of each person and addresses the listener, not as a professional, but as a fellow human. Rita Charon's chapter eloquently evokes and explains the nature of this human-to-human engagement.

In Chapter 2 Eugene Wu and colleagues provide two contrasting views on the SARS epidemic in Hong Kong. Wu was a front-line clinician treating patients with this new and often fatal disease; later, he became a victim of SARS himself. His published scientific account of his own unusual complications of SARS (reproduced from *The Lancet*) is contrasted with his very personal account of being admitted to his own ward by a colleague, watching his fellow doctors and nurses dying in adjacent beds, and contemplating a drastically changed future for himself. A commentary considers the different contributions of the objective (scientific) perspective and the subjective (phenomenological) perspective.

Wu's two very different accounts of his own SARS illness – one as a scientist and the other as a patient – vividly illustrate how personal identity is created through subjective narrative. Richard Rorty argues that human selves emerge at the intersection of old and new uses of language. Wu's scientific case report is reassuringly structured and predictable in form, and uses words in established and agreed-upon ways. His personal narrative account, on the other hand, is much less predictable and uses literary devices such as surprise, suspense, and metaphor, which take us into the domain of the less known: "To have meaning is to have a place in a language game. Metaphors by definition do not"[26] (p 18), although they clearly carry meaning. Quinn comments that "Metaphor is the quintessential challenge to the objectivist account, according to which only literal concepts and propositions can describe the real world".[27]

One reason why some people find medical encounters bruising is precisely because the institutional and professional use of language central to medical practice leaves little room for the personalisation and creative use of language essential to the development of a sense of self. The patient's illness narrative is more than an account of symptoms: it is a form of self-creation through autobiographical literary expression. In Chapter 3 Marilyn Kendall and Scott Murray provide a charming example of the way in which poetic meaning is arrived at in accounts of severe personal illness. Their transposition of recorded narratives in poetic form supports Mishler's argument[12] about the futility of attempting to establish exact correspondences between speech and writing. Meaning is not to be nailed down in ever more exact rules of transcription. Rather, meaning emerges through interpretation and in this study the researchers' finely tuned ears allowed them to discern a poetic structure in narratives of heart failure.

In Chapter 4 Cheryl Mattingly addresses another aspect of severe illness, describing how narratives are used to create and enact hope in the face of it – at a time when the expected narrative may be one of despair and hopelessness. She describes the mother of an African-American child who died at the age of 6 of a brain tumour, but whose various enacted performances during the period of dying, and after the child's death, spoke continually of hope.

Hope, says Mattingly, "is not something discovered or wished. It is painfully created; it is performed", and because healing is so intimately connected to hope *how* hope comes to be performed bears strongly on how healing can be achieved. She draws upon the anthropological work of Victor Turner on healing rituals to show that such rituals have a dramatic or narrative quality that both intensifies personal experience and sets it in the context of a shared story[28–29]. Above all, healing rituals are powerfully emotive, and embody performative or enactive qualities. Mattingly emphasises the importance of "small moments" and the clinician's power to transform routine clinic time into experientially important time. Narrative research, she concludes, concerns not just recording stories perfectly told and structured. It must also acknowledge, and make room for, incomplete fragments and fumblings toward storied forms.

In Chapter 5 Petra Boynton and Annabelle Auerbach offer an analysis of the fragmentary narratives sent as postings to a teenage health website which ran an online feature on self-injury and invited responses from readers. The 260 postings, most of which were from teenagers who actively self-injured, offered a very different picture of this behaviour (and of the sort of person who engages in it) from that provided in standard psychiatric textbooks. Once again, the subjective voice provides insights that more conventional scientific enquiry had failed to uncover.

In Chapter 6 Andrew Herxheimer and Sue Ziebland describe how the Database of Personal Experiences of Health and Illness (DIPEx), an online database of people's narratives of becoming ill, receiving treatment, and – in some cases – dying, adds to "objective" knowledge in more conventional medical databases such as the Cochrane Library. Drawing on the unparalleled experience of the DIPEx team in collecting over 750 narrative interviews, the authors raise and discuss some methodological challenges of this type of research. Their observations about common themes from widely differing narratives illustrate a well-described tension in moving from the individual illness narrative to a more generalised (and generalisable) interpretation. John Berger, in his memorable account of a doctor friend's work in the Forest of Dean, describes the movement between the particularity of illness experience and the universalising dynamic within diagnosis and treatment. He notes that illness and unhappiness both exacerbate a sense of uniqueness.[30] But it is not just diagnosis and treatment that are predicated on comparative exercises: the experience of illness creates a need to compare and share stories. The DIPEx database opens new opportunities for the ill – and those who care for them – to compare and to share their individual stories.

The DIPEx project points to the cardinal role of the listener in narrative, for as Jackson points out, "When storytelling loses its dialogical dimensions it becomes not only self-referential and solipsistic, but pathological"[31] (p 40). Without interpreting audiences, without social affirmation, stories wither. Both Kleinman and Frank have written previously of the critical role of the listener when an illness narrative is being recounted.[9,32] This intersubjective element of narrative is particularly apparent in narratives of dying. In Chapter 7 Arthur Frank describes the way in which accepted ideas about a "good death" (implicitly, common to all who die) can distort the idiosyncrasy and particularity of final experience. The "good death" as lived in reality must tap into individual subjectivity through active dialogue between patient, carers and clinicians. In Chapter 8 Catherine Belling addresses a similar theme and makes a persuasive case for the indispensability of dialogue. In order to complete the story, a witness is needed. "The patient-author, then, cannot tell the end of life in isolation. One more verbal act is essential to establishing narrative closure: told by the physician, this is the account that along with diagnosis, begins the story of dying: prognostication."

For the Russian literary theorist Michael Bakhtin, true dialogue means not cutting off the idea from the voice.[33] It involves being sensitive to the lived experience of the other. In analysing narrative there is a tendency to reify it rather than recognise the evolving and dialogic nature of narrative. For Bakhtin narrative is by its very nature both polyphonic and dialogic, rather than single voiced. In telling a story we not only use words in the way that others have used them before us, we add *our* meanings to theirs and thus build up a jointly authored narrative.[34,35]

In Chapter 9 philosopher Peter Goldie focuses on the central importance of viewpoint to narrative: "If being objective is contrasted with being perspectival, then narrative discourse is not objective, for it is essentially perspectival." Nevertheless, he argues narrative can be objective in the sense of conveying an appropriate evaluation of, and emotional response to, what is recounted.

Goldie's chapter reflects a contemporary shift in the way philosophers conceptualise emotion, seeing it as the means we use to indicate what is important to us. Rather than emphasising the control which culture exercises over shaping feelings, and its power to evoke the same feelings through ritual, this approach finds in emotion recognition of the vulnerability and non-repeatability of human life. Nussbaum has reiterated the role emotions play concerning things that "elude the person's complete control".[36] In this context, the conventional socio-anthropological perspective which invites us to see feelings as reiterated social creations may be misguided, since it seeks to impose a shape on human experience that arguably distorts its essential nature. Feelings are particularly involved where we confront loss and the non-repeatability of human experiences. Nussbaum puts this well:

> [T]o imagine the recurrence of the very same circumstances and persons is to imagine that life does not have the structure it actually has … Aristotle suggests that a certain sort of intensity will be subtracted; for he holds that the thought that one's children (for example) are "the only ones one has" is an important constituent of the love one has for them, and that without this thought of non-replaceability a great part of the value and motivating force of the love will be undercut.[37] (p 39)

On this account, emotions arise from (are embedded in) unique narrative particularities, and they mark some of our profoundest aspirations and vulnerabilities[37] (p 41). Emotions help to situate where we stand in relation to the world in a way that beliefs, by themselves, cannot easily do. Goldie elsewhere has developed a theory of the emotions as cognitive, intentional, and narrative in structure; despite their association with irrationality, they have their origins in purposeful frameworks.[25] Emotions punctuate fears for, and failures in, life projects. According to this reading, rather than being blind and irrational, emotions can offer the most illuminating insights into an individual's standpoint: "Feeling towards is thinking of with feeling" (p 19).

This first section ends with a warning from Yiannis Gabriel in Chapter 10: as narrative becomes the epistemological backlash against the extreme rationalism that was popular in medicine at the turn of the twentieth century, we should beware of reifying the patient's narrative and according it ultimate credibility. Subjectivity, he argues, has an ambivalent relationship to narrative and does not automatically confer authenticity or representational fidelity. Rather, he contends, narratives need to be interrogated (something also emphasised by conventional clinical method) in much the same way as any other claims to truth. He concludes:

> Deception, blind spots, wishful thinking, the desire to please or to manipulate an audience, lapses of memory, confusion, and other factors may help mould a story or a narrative. It is the researcher's task not merely to celebrate the story or the narrative but to seek to use it as a vehicle for accessing deeper truths than the truths, half-truths, and fictions of undigested personal experience.

Section 2: Counter-narratives

An early observation about narrative, and one that has been repeatedly confirmed by the publication of individual accounts of illness,[38–45] is the role of the personal illness narrative in presenting an alternative voice from that offered in the standard biomedical account. Several chapters in this book take up the specific theme of counter-narrative. In Chapter 11 Lesley Jones and Robin Bunton consider stories of deafness. Echoing a contemporary ideological controversy, they tell two deafness stories – "wounded" and "warrior". The wounded are a group of deaf people who despair about their disability, feel outcast from society, and wish that they could hear. The warriors are a minority with their own language and identity, misunderstood and victimised by mainstream society, and fiercely proud of their unique culture. The wounded (mostly those with partial hearing loss or who have lost their hearing late in life) view deafness as a deficiency ("lack of hearing"); the warriors (mostly those who were born profoundly deaf or, as the activists term it, were born Deaf) seek recognition, citizenship, and, in some cases, segregation. This group, argue Jones and Bunton, would view the offer of a cochlear implant (to restore hearing) as an insult, not a cure. A commentary by Philip Zazove, himself congenitally deaf, presents yet another counter-narrative: the overwhelming majority of people with a hearing loss have a partial loss acquired late in life and seek integration with, not segregation from, wider society. Even those who are totally deaf from birth would generally view themselves as deaf, not Deaf. Zazove makes the important observation that despite the fact that what might be called the "Deaf Pride" community are in many ways unrepresentative of deaf people in general, "The warrior mentality of the Deaf community provides enormous support for these individuals by giving them a sense of community and self worth that they otherwise wouldn't get."

In Chapter 12 Clive Baldwin develops the counter-narrative theme by addressing the medical "syndrome" – Munchausen syndrome by proxy (MSbP). His chapter, based on detailed empirical work on the narratives of both parents and doctors, highlights the complex issue of determining any simple notion of "truth" from narratives. As he says (p 219):

> The medical encounter is one of narrative translation and as such is open to mis-hearings and misunderstandings. Patients do not present their symptoms in a clinical manner; they present only those symptoms they think important; can respond to the same question differently depending upon their relationship with the questioner and so on. This translation process is fraught with difficulty and can be used, if uncritically accepted as neutral and benign, against the mother in allegations of MSbP.

In Chapter 13 medical journalist James LeFanu presents the story of parents whose infants were diagnosed as suffering from shaken baby syndrome (SBS). The biomedical account – of a classic collection of injuries caused by a particular form of trauma inflicted by a malign adult who subsequently lies about the sequence of events – was once thought authoritative, objective, and (allegedly) "evidence-based". However, some parents' accounts offer a powerful alternative narrative: a plausible account of accidental trauma, faithfully recounted, followed by a series of humiliating and distressing interviews with professionals characterised by suspicion, distrust, and partial disclosure.

In Chapter 14 Ruth Richardson describes parents' responses to the traumatic experience of finding out about the unconsented removal of their dead child's organs. She recounts that parents perceived pathologists as "quarrying", "ransacking", and "abusing" their children's bodies. As an author, she uses language and metaphor in a new and original manner, to express parents' perspectives. Rorty has noted that "Metaphors are unfamiliar uses of old words, but such uses are possible only against the background of other old words being used in familiar ways"[26] (p 40). In Rorty's account, the innovative use of language is the essence of narrative expression (p 28). Richardson's use of language, however, should not be seen as the rhetorical craft of a creative narrator, but rather as the words of a narrator who adopts the perspective of those who feel wronged. The immediacy, allegiance, and emotion in the voice of her account contrasts with the more detached and effaced voices of the social scientist in Baldwin's chapter and the investigative journalist in LeFanu's contribution, who both utilise verbatim quotes as a surrogate voice. Differences in narrative voice show how powerfully nuanced narrative accounts can be, and the many semantic levels at which they can operate.

The second section ends with paediatrician and epidemiologist Tom Newman presenting, in Chapter 15, two stories that "hit the media" in the United States – concerning a baby who developed brain damage following high plasma bilirubin levels at birth (neonatal jaundice), and another baby who died in an air crash after travelling unrestrained by a seat belt. In both cases, an official, scientific narrative argued that these infants were merely the unlucky victims of million-to-one risks. But in both cases the emotive personal story of the mother overshadowed the measured advice and codified evidence of the experts. Something, each mother argued, must be done – and it was. Brian Balmer, a philosopher specialising in public understanding of scientific knowledge, offers a commentary on why stories can be more powerful than statistics.

Section 3: Meta-narratives

In *The Postmodern Condition*,[46] Jean-François Lyotard defines meta-narratives as the grand narratives of wider society within which we interpret our personal world and experiences. Christianity, Marxism, feminism, modernist science, and the various historical diaspora of displaced groups are all examples of over-arching stories that provide perspectives on the nature of the social world, where it came from, and where it is going. Because, as Jackson says[31] (p 16), "*storytelling tends to interdigitate and reinforce extant social boundaries*", personal narratives inevitably reflect and incorporate wider social meanings.

Gareth Williams in Chapter 16 describes the way in which personal narratives of ill health incorporate a lay understanding of the prevailing social forces that bear upon ill health. He refers to the way in which these "knowing narratives" not only help construct autobiographies of ill health, but also relate personal to social inequalities. In a very different example, in Chapter 17 Vieda Skultans writes autobiographically of her experience as an infant refugee in post-war Germany. The chapter highlights how very early narrative memories are shaped by the historical circumstances of refugeedom – specifically, the need for connectedness and a sense of belonging to a wider community in the face of disconnection from a known and secure world.

The social world is not merely reflected in personal narratives: it constrains and impoverishes our interpretation of them. In Chapter 18, for example, Cathy Riessman reinterprets an illness narrative she collected in a field study some twenty years ago, and identifies a particular social world contained within the personal illness narrative of her narrator, Burt, who suffered from multiple sclerosis in the early 1980s. In her present-day reflections, Riessman couches Burt's perceptions of "being alone" in the particular historical and geographical context of a United States before disability rights had begun to emerge as a movement. Disabled people then spent their time at home, contemplating (and accepting as inevitable) their damaged bodies and lost social roles. A contemporary re-reading of her field interview notes highlights something that was curiously inapparent to her as a researcher at the time: Burt's narrative lacks any perspective on the social injustice of his situation.

Riessman's chapter illustrates an important principle: that even though narrative is a uniquely creative form, we never have an entirely free hand in its lived construal. MacIntyre elaborates this point:

> We are never more (and sometimes less) than the co-authors of our own narratives. Only in fantasy do we live what story we please. In life, as both Aristotle and Engels noted, we are always under certain constraints. We enter upon a stage which we did not design and we find ourselves part of an action that was not of our making. Each of us being a main character in his own drama plays subordinate parts in the dramas of others, and each drama constrains the others.[47]

The notion of the narrator as the living bearer and shaper of language, and as an independent actor in life's drama, challenges the more conventional notion of the passive patient seeking advice, help and sympathy from the health professional. Goffman (quoted by Cathy Riessman on page 312 of this book) puts it thus: “what talkers undertake to do is not to provide information to a recipient but to present dramas to an audience”. Paul Bate, an organisational anthropologist, describes in Chapter 19 the story of a facilitated and researched quality improvement initiative in a UK NHS hospital trust. The conventional narrative of organisational change, he argues, is couched in “the vocabulary of coercion, competition, tyranny, hegemony, control, subjection, engineering, manipulation, domination, subordination, resistance, opposition, diversity, negotiation, obedience, and compliance”. A different approach uses different vocabulary: *“cooperation, convergence, coherence, integration, and consensus”*, for which the development of a shared story can prove the critical mechanism. In emphasising the critical role of enacting stories as a vehicle for collective action, he cites Kling on p 337 of this book:

> Social movements are constituted by the stories people tell to themselves and to one another. They reflect the deepest ways in which people understand who they are and to whom they are connected … They are constructed from the interweaving of personal and social biographies – from the narratives people rehearse to themselves about the nature of their lives … The construction of collective action, therefore, is inseparable from the construction of personal biography, from the ways, that is, we experience the imprecation of our individual and social selves.

This notion of a social world constraining and shaping the unfolding of narrative is given a different twist by two authors who write on how science itself takes a storied form and of how its emplotment is shaped by social forces. In Chapter 20 Trisha Greenhalgh reinterprets the writing of philosopher Thomas Kuhn, who developed the notion of paradigmatic research traditions. She argues that the unfolding of scientific research within any particular tradition is an inherently narrative phenomenon. Using a detailed example from a recent cross-disciplinary systematic review, she argues:

> If research unfolds historically over time (with one study leading directly, though never with mechanistic predictability) to the next study; if research traditions often (and perhaps always) follow a common plot; if the unfolding of the tradition depends on a cast of different characters (with experimenters, gurus, faithful footservants, obsessional puzzle-solvers and doubting Thomases all having their accorded parts to play in different phases); if negotiated (and, necessarily, shared) meanings and models are a prerequisite for focused, directed scientific activity – we surely have the makings of an important new hypothesis: that no research field can be understood without attention to the over-arching storylines that describe its progress.

On a similar theme, Allan Young in Chapter 21 offers a hypothesis that the "illness" of post-traumatic stress disorder is less a scientific "fact" than a social construction by researchers. Furthermore, he argues, the cognitive techniques that scientists unconsciously use to further their research have extraordinary similarities to the abductive reasoning used by characters in fictional detective stories: constructing a (somewhat artificial) puzzle and then solving it. Abductive reasoning, he argues, involves five key logico-literary devices: analogy (using a well understood phenomenon as a model for explaining a poorly understood one), synecdoche (depicting the whole by one of its parts), metonym (implicating one feature by reference to another which is contiguous in time or space), induction (a generalisation inferred from multiple instances or observations), and deduction (inferring a particular instance from general principles). These are all, Young argues, devices grounded in literary techniques, and we should recognise the ultimately subjective and arbitrary influences they bring to science.

One characteristic of meta-narratives is that, unlike the particular individual story being recounted, they are not immediately apparent to the listener or reader. Indeed, the meta-narrative embraces (and assumes) a particular world view and ideology, which teller and listener tend to take for granted. The first task of those who seek to challenge a particular meta-narrative is to deconstruct it and lay bare these various assumptions and the communicative and literary devices used to perpetrate them, as Young has done with one particular scientific research tradition.

In Chapter 22, David Harper offers a similarly detailed and critical exposition of the meta-narrative that both drives and seemingly justifies healthcare policy making in relation to the seriously mentally ill. Using a recent UK government White Paper on compulsory detention of people with mental illness[48] he demonstrates how metaphor, rhetorical devices, and implicit emplotment are used to present a particularly polarised view of the dangers of one policy option (caring for people with psychosis in the community) and the benefits of another (locking them away). The over-arching discourse of this particular White Paper, Harper argues, is not one of the provision of care for a particular group of patients but one of protecting the public from a group of dangerous individuals who are a menace to "normal" people. Quantitative data on actual risk of harm from such individuals are overlooked through a rhetorical device known as narrative accounting – that is, offering qualitative estimates such as "most people" or "the risk is substantial". This, argues Harper, reflects a deeper ideological meta-narrative in contemporary policy making circles, which is inherently normative, coercive, and dismissive of individual liberty.

The book concludes with a chapter by Brian Hurwitz which considers narrative temporality in stories, clinical relationships, and case histories.

Medical processes generally unfold in a linear fashion over time. In part, this results from their depiction within a biological rather than an experiential order, and from a convention that edits out many of the twists and turns of patients' ill health experiences, particularly those thought to carry no clinical (that is, causal) significance. But as Peter Brooks has pointed out, plotting – an activity which is common to graphic and narrative depiction – links what happens (in the future) with causal determinations in reality, imagination or fiction.[49] Linear temporal unfolding, a feature of first person pathographies however richly textured, as much of case histories, is usually revealed by segmentation of the story into medico-biographical eras – before, at the beginning, during, and at the end of an illness – the tempo of each varying. Time is unevenly compressed, stretched, and gaps are created in order to generate an appropriate "bird's eye, after-the-fact version" of what happened.[50] Pathographies and case histories instantiate Paul Ricoeur's observation that "to narrate a story is already to 'reflect upon' the event narrated".[51] The narrative of fact is never a simple mirror of events. It is a recounted version of what happened.

Narrative voices

This volume demonstrates the need (and the justification) for a re-valuing of the subjective, the perspectival, and the personal in medicine and health care. But whilst there is a strong theoretical basis for promoting the principles of narrative more widely in clinical medicine, we should recognise just how profound is the change required. Byron Good, the Harvard anthropologist, has painstakingly demonstrated the difficulty medicine has in *not* excluding, let alone in coming to terms with, the subjective. Indeed, he argues that medical history taking should be seen as providing lessons in the exclusion of the subjective: "The central speech acts in medical practice are not [about] interviewing patients but presenting patients"[52] (p 78). Categories and concepts emerging in medical interviews fashion the written case history, but "the write-up is not a mere record of a verbal exchange. It is itself a formative practice, a practice that shapes talk as much as it reflects it, a means of constructing a person as a patient, a document and a project"[52] (p 77). Thereby, traditional medical education teaches students to shape and take control of the patient's oral contribution.

Howard Waitzkin sees the medical encounter as "a micro-political situation, in which the control of information reinforces power relations that parallel those in the broader society, especially those related to social class, gender, race and age".[53] In "prescribing" particular behaviours for a healthy life, for example, medical practitioners can strengthen and re-articulate particular social institutions and ideologies – most obviously by couching the possibility of future illness in terms of individual risk behaviour rather than in terms of (say) socioeconomic inequalities, gender roles, or political inaction. Simon Sinclair's ethnographic study of medical students and their education adopts a similar view. In *Making Doctors: An Institutional Apprenticeship,* he describes the important business of clerking a patient: "The history as 'given' by the student to the doctor is, in effect, a reconstruction of the patient's experience as if the patient were a doctor".[54]

Through standardised questioning and a cut and paste technique, the patient's experiential account is transformed into a medical case, consisting of presenting complaint and history. In the process of history taking and case presentation much that gave meaning to the patient's narrative is thereby eliminated. But Gilbert Lewis, a medically trained anthropologist, views the clinical case history and medical record not as "a narrative of illness, nor a description of the encounter between the doctor and the patient, but rather as a statement which combines what the patient complained of with answers to some directed questions and observations made by the doctor".[55] In his account of the case history, "the patient's own words" are on an equal footing with the doctor's questions and observations.

What Lewis' account appears to ignore is the politics of language and quotation. How much of the original meaning of what the patient says is preserved when re-sited amongst the words of others? Mishler describes the way in which doctors maintain control and continuity of discourse, by relocating patients' talk to a different semantic world.[56] In the medical interviews which Mishler analysed, the interlocutor exercises total control over both the questions asked and the shape of acceptable answers.[56] Similarly, in the composing of questions, certain kinds of structured and semi-structured interviews determine the shape of possible answers. Mishler terms this approach, the "stimulus response model" of interviewing;[57] it leaves no space for attempts by patients or ethnographic subjects to seek to renegotiate the terms of interviews, or to introduce new priorities for discussion.

Barrett, a psychiatrist turned anthropologist,[58] who has a finely tuned ear for taken-for-granted truths and metaphorical turns of phrase, sees the case history as a "segmented object", in which the distinctive contributions of nurses, social workers, and psychiatrists are hierarchically organised and welded into a "testament to consensus". His discussion of the written construction of schizophrenia shows how case notes systematically eliminate subjectivity, excluding common sense understandings and empathy, which come to be replaced by an objective distance between interviewer and interviewed.

Katherine Montgomery Hunter makes out a far more radical case for the narrative structure of medical knowledge. It is because "the imperfect fit between biological knowledge and the expression and treatment of disease in the individual leaves room for variants, surprises, anomalies"[13] (p 67) which find narrative expression in clinical anecdotes, that medical degrees have typically been divided between the biological sciences and clinical apprenticeships organised around the narrative presentation of illness as case studies. But narratives of doctors are structured by a different narrative logic from those of patients: "The determination of the diagnosis and the consequent choice of treatment bring the medical plot to a close. … In the patient's story, closure is governed by a different plot, one which has a structure almost as invariant as the medical one. The restoration of health or its inalterable loss will close the story, just as loss of health real or foreshadowed was its genesis" (p 127). It is not that the patient's story is irrelevant to the medical story but it is swallowed up and given a new meaning by the medical story: "Once it has yielded its information, the patient's version of the events of illness, as well as the life out of which it is told, is often ignored. Like the Old Testament in the reign of the New, the patient's story has been superseded – not by being forgotten or denied or controverted but by being interpreted" and transformed (p 131). This retelling of the story affects the patient's life in different ways, "sometimes leaving scarce a mark, sometimes altering it with earthquake force" (p 132).

Despite ethnographic studies which demonstrate how far much of medicine is still removed from the principles set out in this book, the medical meta-narrative is itself changing. Once paternalistic, autocratic, and segregationist, the medical profession increasingly seeks to democratise its own ranks, work with (and learn from) other professional groups (notably nursing, sociology, economics, and ethics) in seeking to develop and promote "patient-centred" clinical care. Doctors and medical students are encouraged to adopt open-ended questioning techniques and thereby to elicit storied responses and reports (see, for example, Byrne and Long's 1976 study of doctors talking with patients[59] and, more recently, Moira Stewart *et al*[60]).

In his recent book *Narrative Based Primary Care*, John Launer points to the growing acceptance by doctors and health carers "that professionals do not have a monopoly on describing people's experiences when they are ill, or on telling them what to do about it"[61] (p 3). The claim to a monopoly on the truth in the past reflected a monopoly on power as much as it may have reflected a privileged method (science) for accessing a persuasive version of the truth.[62] Just as the centre of power in healthcare relations is shifting away from the grasp of professionals and towards the control of patients,[63] so the notion of healthcare truth is becoming more pluralistic and perspectival.

David Morley's collection of memoirs, poems, and short stories by patients, health carers, and writers springs from these realisations.

Commissioned and paid for by Birmingham Health Authority, which distributed 25 000 copies to its entire work force, its contributors powerfully contest the institutional, medical, authorial control of healthcare narratives. The book exemplifies an emerging dynamic of resistance to conventional institutional, professional linguistic forms of depiction in health care.[64]

In reading this volume many voices are heard. Voice draws attention to the timbre, expressiveness, and tone with which a story is told, to the presence, involvement, and moral position of its author. Voice also links to the idea of unity and control of a literary work, and to the individuality of narrators. But much as voice owes to literary and film studies, its meaning in healthcare is invigorated with politics, where it stands for the assertion of interests of previously ignored experience and points of view.[65–68] In the chapters that follow we encounter the raw presence of narrators, as in Mattingly's account of a mother's reaction to her daughter's diagnosis of a terminal illness; in a researcher's reflective voice in dialogue with earlier speakers, as in Riessman's chapter; in the effaced presence of the empirical investigator who gives focused attention to the voices of mothers accused of MSbP, as in Baldwin's chapter; in the author who *speaks out* and *speaks up* for a cause, as in Richardson's chapter; and in the voice of the frightened child-adult caught up in a disconnected world, as in Skultans' chapter.

In presenting the creative diversities of subjective and objective viewpoints that pervade healthcare practice, today, *Narrative Research in Health and Illness* engages many personal, moral, institutional, and social aspects of health, and touches on issues of power and empowerment. In the variety of interdisciplinary methods and conceptual frameworks which the volume encompasses, we venture to hope that it properly and comprehensively displays the state of narrative studies in health at the start of the twenty-first century.

Endnotes

i Daston points out that objectivity, rather than being an unchanging benchmark for human knowledge, has a history of shifting meanings[18] (p 597). For example, objectivity refers not to attempts to eliminate the subjective idiosyncrasies of observers but also to eliminate the idiosyncrasies of the natural world in order to produce standardised working objects. The atlas became the paradigm for this kind of object in the late nineteenth century. "The atlas aims to make nature safe for science; to replace raw experience – the accidental, contingent experience of specific individual objects – with digested experience"[19] (p 85). Pictures and atlases created through mechanical techniques of reproduction came to be regarded as "the words of nature itself" (p 116). The association of standardised imagery with objectivity had important implications for the understanding of human behaviour and promoted the pictorial representation of deviant categories such as the insane and the criminal.[20] In other words, knowledge of other people was to be obtained

> through observation, preferably aided by mechanical standardising techniques. But the visual representation of others tells us more about the root metaphors and stereotypes of a culture than it does about lived experience.[21]

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