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Narrative based medicine

Why study narrative?

Trisha Greenhalgh, Brian Hurwitz

This is the first in a series of five articles on narrative based medicine

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What is narrative?

One day when Pooh Bear had nothing else to do, he thought he would do something, so he went round to Piglet's house to see what Piglet was doing. It was snowing as he stumped over the white forest track, and he expected to find Piglet warming his toes in front of the fire, but to his surprise he saw that the door was open, and the more he looked inside the more Piglet wasn't there.¹

This excerpt from the opening chapter of a well known children's story illustrates a number of features of narrative as a linguistic form. Firstly, it has a finite and longitudinal time sequence—that is, it has a beginning, a series of unfolding events, and (we anticipate) an ending. Secondly, it presupposes both a narrator and a listener whose different viewpoints affect how the story is told. Thirdly, the narrative is concerned with individuals; rather than simply reporting what they do or what is done to them it concerns how those individuals feel and how people feel about them. Both Pooh Bear, trudging hopefully through the snow, and Piglet, mysteriously absent from his usual place beside the fire, are already characters in the story rather than merely objects in the tale.

The narrative also provides information that does not pertain simply or directly to the unfolding events. The same sequence of events told by another person to another audience might be presented differently without being any less "true." This is an important point. In contrast with a list of measurements or a description of the outcome of an experiment, there is no self evident definition of what is relevant or what is irrelevant in a particular narrative. The choice of what to tell and what to omit lies entirely with the narrator

Summary points

The processes of getting ill, being ill, getting better (or getting worse), and coping (or failing to cope) with illness, can all be thought of as enacted narratives within the wider narratives (stories) of people's lives

Narratives of illness provide a framework for approaching a patient's problems holistically, and may uncover diagnostic and therapeutic options

Taking a history is an interpretive act; interpretation (the discernment of meaning) is central to the analysis of narratives (for example, in literary criticism)

Narratives offer a method for addressing existential qualities such as inner hurt, despair, hope, grief, and moral pain which frequently accompany, and may even constitute, people's illnesses

The lost tradition of narrative should be revived in the teaching and practice of medicine

and can be modified, at his or her discretion, by the questions of the listener.

And finally, the narrative is absorbing. It engages the listener and invites an interpretation. It offers us the experience of "living through, not simply knowledge about" the characters in the story.²

Narratives in the experience of illness and healing

We "dream in narrative, daydream in narrative, remember, anticipate, hope, despair, believe, doubt, plan, revise, criticise, construct, gossip, learn, hate and love by narrative."³ Episodes of sickness are important milestones in the enacted narratives of patients' lives. Thus, not only do we live by narrative but, often with our doctor or nurse as witness,⁴ we fall ill, get better, get worse, stay the same, and finally die by narrative too.

The narrative provides meaning, context, and perspective for the patient's predicament. It defines how, why, and in what way he or she is ill. The study of narrative offers a possibility of developing an understanding that cannot be arrived at by any other means. Doctors and therapists frequently see their roles in terms of facilitating "alternative stories that make sense from the patient's point of view."^{5 6} It has been argued that in psychotherapy the role of the therapist goes further: the therapist should assist the patient in his or her attempt to construct and work through the unconscious elements of a half written personal story.⁷



LIANE PAYNE

Why study narrative?

In the diagnostic encounter, narratives:

- Are the phenomenal form in which patients experience ill health
- Encourage empathy and promote understanding between clinician and patient
- Allow for the construction of meaning
- May supply useful analytical clues and categories

In the therapeutic process, narratives:

- Encourage a holistic approach to management
- Are intrinsically therapeutic or palliative
- May suggest or precipitate additional therapeutic options

In the education of patients and health professionals, narratives:

- Are often memorable
- Are grounded in experience
- Encourage reflection

In research, narratives:

- Help to set a patient centred agenda
- May challenge received wisdom
- May generate new hypotheses

Understanding the narrative context of illness provides a framework for approaching a patient's problems holistically, as well as revealing diagnostic and therapeutic options. Furthermore, narratives of illness provide a medium for the education of both patients and health professionals and may also expand and enrich the research agenda (box). Indeed, it is thought that anecdotes, or "illness scripts," may be the underlying form in which we accumulate our medical knowledge.^{8,9} Medical students rely on anecdotes of extreme and atypical cases to develop the essential ability to question expectations, interrupt stereotyped thought patterns, and adjust to new developments as a case unfolds.¹⁰

The dialogue in the box took place between one of us (BH) and a patient attending a diabetic clinic in general practice. The conversation was recorded on tape and is reproduced almost verbatim with the patient's consent. There are a number of important points in the story. Firstly, the immediacy of the patient's voice—his particular way of explaining things—cannot be ignored by a listener or reader, although this would be impossible to capture were the story to be retold in the standard forms used for medical histories. Secondly, the onset of this man's disease is inextricably embedded in a narrative structure: he recounts with almost choreographic precision how the symptoms unfolded together with his efforts to communicate them.

Despite the passing of 30 years, the patient's utter helplessness at the hands of his medical attendants is chilling. It is not simply that his doctor did not seem to listen to him: the doctor's advice and inaction were predicated on an entirely different story from the one that required urgent intervention. Asher was graphic in drawing attention to the dangerous tendency of clinicians to see the expected and unconsciously to dismiss the anomalous: "We have to beware of this suppressive faculty which, by producing selective deafness, selective blindness and other sense rejections, can

so easily suppress the significant and the relevant."^{11,12} The box describes a new initiative for collecting these stories and utilising their educational potential for both patients and health professionals.

The study of meaning

Even the most pompous professors have been known to warn their students, "Listen to the patient: he or she is telling you the diagnosis." A more sophisticated view holds that when doctors take a medical history they inevitably act as ethnographers, historians, and biographers, required to understand aspects of personhood, personality, social and psychological functioning, and biological and physical phenomena.¹³

The notion of interpretation—the discernment of meaning—is a central concern of philosophers and linguists, but it is a concept with which doctors and other scientists are often unfamiliar, and hence uncomfortable. Hunter, a professor of literature with a strong involvement in medical education, writes, somewhat controversially, that clinical medicine "shares its methods of knowing with history, law,

Robert's story

Doctor: Tell me how you first found out that you were diabetic.

Patient: Well my tongue started to get very, very dry and also I was drinking excessive amounts of liquid and also I had an upset stomach. So I went to my doctor and told him all this, and all he told me was that I had an "upset stomach." And I told him then that I think I am a diabetic and he told me that I was talking a load of rubbish.

Doctor: Why did your symptoms suggest diabetes to you?

Patient: Because I have been with a diabetic before who has now died. I had known him since he was 9 years old, so the symptoms I had, he [had] described to me before. And that is how I knew I thought I was a diabetic. So I went to another doctor and he told me the same thing: that I had an upset stomach. So I waited and waited and waited. Then I decided to go back to my doctor, when my water was starting to crystallise, and he told me that I had VD.

Doctor: What do you mean?

Patient: When I was passing the water, the end of my penis started getting all white and also sometimes when the water hit the pan it was starting to go clear white.

Doctor: What happened next?

Patient: Well, I decided to go down to the VD clinic . . . and I went in there on the Friday night and I handed him the letter. And he read it and he said to me, "What do you think you have got?" And I said, "I think I have got diabetes." And he said, "What [idiot] sent you here? He should have seen this before you were sent here." So he said to me, "Look I cannot do anything for you tonight, but please report down to the hospital the next morning." (That was Saturday morning.) So I went back home and I came down the Saturday morning, but with me walking down on the Friday night and the Saturday morning, which normally takes me about 5 minutes, took me 35 minutes just to reach the bus stop.

Doctor: Why was that?

Patient: Because I was so weak I could hardly move at all. So I went down, got down to [the hospital], went in and told the [nursing] sister at the reception that I would like to see somebody from the diabetic clinic. And she read the letter. Then she told me that I could not get an appointment until a fortnight. At this stage I was really very angry and I started shouting at her. As that started, a nurse came out from casualty and she read the letter. As soon as she read the letter she shouted to a nurse to get a wheelchair, she dumped me in the wheelchair, and took me straight upstairs to the diabetic clinic.

The Database of Individual Patient Experience

The aim of the Database of Individual Patient Experience (DIPEX) is to collate, index, and publish in narrative form the illness experiences of health service users and participants in clinical trials. It is envisaged that the database will eventually be able to be accessed by patients, their families and carers, self help groups, policymakers, researchers, social scientists, medical and nursing educators, as well as clinicians.

The core team of six researchers is preparing to undertake a systematic overview of the methods that have been used to collect patients' illness experiences in four areas: breast cancer, pelvic pain, high blood pressure, and screening for bowel cancer. After the review is completed, the team will decide on the appropriate method for compiling their database. They anticipate that a major contribution will come from literature reviews and from new primary research done in the form of semistructured interviews.

The team have analysed pilot questionnaires completed by patients after outpatient or inpatient hospital visits. The final form of the accounts on the database will be personal stories firmly anchored to the diagnosis and stage of the patient's condition. Whenever possible, the stories will take a temporal perspective. Hence, rather than giving a snapshot of a patient's feelings and concerns at one time during an illness, the narrative will follow these feelings and concerns through a sequence that begins before diagnosis and continues through the clinical encounter, the investigations, the development of a management plan, and the resolution or progression of the disease.

Further information about the project can be obtained from Pamela Baker at the General Practice Research Group, Institute of Health Sciences, Oxford OX2 7LF, or from pamela.baker@dphpc.ox.ac.uk.

economics, anthropology, and other human sciences less certain and more concerned with meaning than the physical sciences. But unlike those disciplines, it does not explicitly recognise its interpretive character or the rules it uses to negotiate meaning.¹⁰ She is puzzled by the medical profession's preoccupation with the gold standard of science in clinical practice, and believes that medicine is better characterised as a "moral knowing, a narrative, interpretive, practical reasoning."^{14 15}

A lost tradition

The oral tradition of myths and legends, which are continually recreated by word of mouth in successive generations, still features prominently in many non-Western societies and impacts profoundly on the experience of health and illness in these societies.¹⁶ Perhaps it is partly because Western culture has lost its grip on this oral tradition that the skills of listening to, appreciating, and interpreting patients' stories are only rarely upheld as core clinical skills in medical curriculums. Much of the current emphasis in medical training is on the student acquiring the ability to express a patient's problem in the structured and standardised format that has come to be known as the "medical history" in the United Kingdom and "clinical clerking" in North America. It has been shown that somewhere between the first year and the final year of

medical education, undergraduate students exchange a native facility for eliciting and appreciating patients' narratives for the learned expertise of constructing a medical history.¹⁷

Narratives frequently appear in a vestigial form in the conventional clinical encounter of modern times. Certain descriptions of symptoms appear as fragments torn from elaborate stories and are alighted on by clinicians as especially revelatory: "My shortness of breath always gets worse when I lie down but the funny thing is the pain only comes on when I climb stairs," or "I was washing the dishes when everything went black—it was like a curtain coming down." Less familiar experiences may be just as important to the patient but the value of such "classic" symptoms to doctors as readers of signs is akin to a mirror held up to nature: so closely are they aligned to physiological and pathological mechanisms that the story fragments faithfully portray, in a linguistic form, particular biological dysfunctions.

At its most arid, modern medicine lacks a metric for existential qualities such as the inner hurt, despair, hope, grief, and moral pain that frequently accompany, and often indeed constitute, the illnesses from which people suffer.¹⁸ The relentless substitution during the course of medical training of skills deemed "scientific"—those that are eminently measurable but unavoidably reductionist—for those that are fundamentally linguistic, empathic, and interpretive should be seen as anything but a successful feature of the modern curriculum.

The core clinical skills of listening, questioning, delineating, marshalling, explaining, and interpreting may provide a way of mediating between the very different worlds of patients and health professionals. Whether these tasks are performed well or badly is likely to have as much influence on the outcome of the illness from the patient's point of view as the more scientific and technical aspects of diagnosis or treatment.¹⁸

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