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Narrative-Based Medicine: Potential, Pitfalls, and Practice

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Introduction

Narratives have always been a vital part of medicine. Stories about patients, the experience of caring for them, and their recovery from illness have always been shared—among physicians as well as among patients and their relatives. With the evolution of “modern” medicine, narratives were increasingly neglected in favor of “facts and findings,” which were regarded as more scientific and objective. Now, in recent years medical narrative is changing—from the stories about patients and their illnesses, patient narratives and the unfolding and interwoven story between health care professionals and patients are both gaining momentum, leading to the creation or defining of narrative-based medicine (NBM). The term was coined deliberately to mark its distinction from evidence-based medicine (EBM); in fact, NBM was propagated to counteract the shortcomings of EBM.^{1,2} But what is NBM? Is it a specific therapeutic tool, a special form of physician-patient communication, a qualitative research tool, or does it simply signify a particular attitude towards patients and doctoring? It can be all of the above with different forms or genres of narrative or practical approach called for depending on the field of application.

In this article we will give a systematic overview of NBM: a short historic background; the various narrative genres; and an analysis of how the genres can be effectively applied in theory, research, and practice in the medical field, with a focus on possibilities and limitations of a narrative approach.

In medical practice, three different, though overlapping, areas can be distinguished:

1. Learning the patient's and the caregiver's perspective for research and training. Classification of various narrative forms or genres will be included in this discussion.
2. The narrative approach in medical practice, through understanding the narrative structure

of medical knowledge, and narrative-oriented, physician-patient relations.

3. Narratives as evidence—narratives from social science research and narratives derived from medical practice and patient encounters are a source of knowledge for evidence, beyond the gold standard of randomized controlled trials of evidence-based medicine.

Background

Medical narrative is changing: a movement from the physician's narrative to patient's narrative. In modern times, the dominant medical narrative has been the physician's narrative in the form of the classical objective biomedical scientific report. The medical narrative nowadays, David Morris points out, increasingly recounts the patient narrative.³ In the late 1980s, Polkinghorne and others spoke about a “narrative turn” in the medical field—narratives are now seen as a useful resource for understanding the individual, patient-specific meaning of an illness.⁴ Narratives—especially patient narratives—incorporate the question of causality and thus foster an understanding of the patient's illness perception. In the words of Greenhalgh and Hurwitz, “Narrative provides meaning, context, perspective for the patient's predicament. It defines how, why, and what way he or she is ill. It offers, in short, a possibility of understanding which cannot be arrived at by any other means.”⁵ This understanding, we believe, is also true for stories about being a medical professional and caring for the sick in times of growing economic and institutional constraints; and with the increasing dominance of the economic narrative.

Narrative Structure of Medical Knowledge

The development of NBM has to be understood in the context of patient-centered approaches—bringing



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the patient as a subject back into medicine. This has been central to Viktor von Weizsäcker's work on psychosomatic medicine.^{6,7} He demanded inclusion of the patients' experience into the medical endeavor. An illness narrative tells us not only about a specific medical case, but about the intensive, ultimate, and most authentic reality of life or death of a person. According to von Weizsäcker, the illness narrative is not only a description of something pathological; it is the description of the life of the illness in that specific individual human being.⁸ This subjective approach can also be found in patient-oriented, physician-patient communication and relations extending back to Carl Rogers⁹ and Michael Balint.¹⁰ In 1998, Greenhalgh and Hurwitz pointed out that the meaning of narratives in the physician-patient interaction becomes apparent in those subjective, patient-oriented encounters, especially in Balint groups.⁵

Kathryn Montgomery Hunter was one of the first to point out the narrative structure of medical knowledge:

“Narrative is the ultimate device of casuistry in medicine (as in theology and law), which enables practitioners who share its diagnostic and therapeutic worldview to fit general principles to the single case and to achieve a degree of generalization that is both practicable and open to change.”^{11p46-7}

In that sense narratives can be understood as the bridge between the evidence of large scale randomized-controlled studies and the medical art of applying this knowledge to a single case. EBM and NBM thus must be understood in complementary terms. Peter F Matthiessen points out: In medical practice, both aspects, the search for laws of cause and effect and the description of the specific, unique and singular cannot be pursued separately;¹² they are inextricably intertwined. In the process of turning medicine toward a natural science, the effort to reach ever more objective findings led to neglect of the subjective dimensions of medical practice. Matthiessen argues that an incorporation of the subjective areas (for example in single case studies) would result in a higher objectivity within medicine. According to Matthiessen, a narrative culture in medicine would highlight the interpretative and judgmental character of diagnostic statements. It would further clarify the intrinsic contextuality of knowledge. He concludes that objectivity in that sense would be the methodological inclusion of the subjectivity of all perception and knowledge.¹² The latest development in the field has led to the endeavor to integrate the approaches

of EBM and NBM in a program called “narrative evidence-based medicine” that, according to one of its founders Rita Charon, “recognises the narrative features of *all* data and the evidentiary status of *all* clinical text.”²²

The Different Genres of Narratives

Narratives about being ill and caring for the ill provide insight into respective experience and thus could foster mutual understanding—not only from the medical side for their patients but also from patients for their caregivers. Narratives also give further insight into the cultural and sociohistoric context of medicine and being ill. Four genres of narrative can be distinguished:

1. Patient Stories—Classic Illness Narratives

Patient stories allow making sense of their suffering and how it feels from the inside. They offer a biographic and social context of the illness experience and suggest coping strategies. They also create potential for personal development. Jeffrey K Aronson, MD, MBChB, FRCP, DPhil, Professor in the Department of Clinical Pharmacology at the University of Oxford, has created an annotated bibliography of about 270 books on pathographies and autopathographies, available at: www.clinpharm.ox.ac.uk/JKA/patientstale.¹³

2. Physicians' Stories

Autobiographical accounts about life as a physician and caring for those who are sick have a long history—one prominent example being the writings of Anton Chekhov.¹⁴ Physicians' stories can also contribute to the rehumanization of medicine in the same way as patient narratives.¹⁵ After all, human beings deliver medical care. A special genre constitutes stories about physicians as patients. Reflections on physicians' own vulnerability are not very prominent, and even less so in public; however, these accounts show how physicians' illness experiences changed their understanding of their professional role and their relation to their patients. DasGupta and Charon tried to foster that kind of reflexivity¹⁶—ie, taking on a reflexive stance toward their own experience—in medical students, asking them to write about a time of experienced bodily vulnerability or suffering. This means of reflection helps physicians to develop empathy and understanding for the situation of their patients. DasGupta and Charon conclude: “The personal illness narrative allows the reader-writer to more fully enter the reality of the patient world by recognizing, describing, and integrating the similari-

ties in her own personal experiences and those of the patient.”¹⁶ It can also counteract the neglect of their embodiment that is intrinsic, unfortunately, to the medical system.¹⁶

3. Narratives about Physician-Patient Encounters

Illness, and the process of being ill, is formed and articulated in the physician-patient encounter. The patients’ experience of symptoms is interpreted by physicians’ medical knowledge, eventually leading to a diagnosis and respective therapeutic intervention. This in turn changes patients’ narratives about what they experience. As they “make sense” of their sensations, the medical perspective on them plays a vital part. There is an ongoing debate about the degree of a physician’s influence in creating the patient’s story¹⁷⁻¹⁹ and we will suggest a way to look at it in the next section of this paper. Nevertheless, physicians have the potential to take on an important supportive role in the creation of the illness narrative: to create and to formulate new stories, as family physician John Launer points out, and thus help patients in their coping process and even contributing to their personal growth.²⁰ The illness narrative has to be understood and seen as being part of a patient’s life story. Of course an inverse effect is possible in that patients feel devalued by medical judgment of their existence, especially if it is a strictly pathologic judgment without account of the still healthy and valuable aspects a person has even in severe illness or when the whole person story is truncated merely to the illness narrative.

4. Grand Stories—Metanarratives

In the background of individual narratives there are always grand narratives of sociocultural understandings of the body in health and illness. They are described in studies of medical history or the history of the body²¹—such as *The Culture of Pain* by David B Morris²² or *Fragments for a History of the Human Body* by Michael Feher et al,²³ and the dominant medical discourse in particular as has been analyzed by, for example, Michel Foucault.²⁴ This influences both the caregivers’ and the patients’ view of illness and of the sick body.²⁵

The Potential of Narratives in Communication

Published narratives tend to be told in reflected and elaborated ways. But narratives are also shared in and created by communication, ie, a “speech act.” A speech act constitutes a specific form of text genre with a specific linguistic text structure that is distinct

from other forms, for example an argument or a report. These nucleus narratives can also emerge in a physician-patient consultation. There are five characteristics of narratives in a speech act that are important for medical practice. These characteristics:

1. Consist of distinctive and recognizable phases: orientation, complication (an incident that is problematic or out of the ordinary; ie, the part of the story that makes it worth telling), evaluation, coda²⁶
2. Always have a specific addressee (and thus can never be told in the same way twice)
3. Always are about an individual and what s/he experiences/feels
4. Contain information that is not an essential part of the story—the content is the narrator’s choice, what s/he regards as relevant to the story and thus is an act of meaning creation
5. Have the potential to “draw us in” and thus, in the words of Greenhalgh/Hurwitz enable the experience of “living through” and not only “knowledge about” (emotionality).⁵

Narratives on the level of a speech act follow an intrinsic drive for completion: to give relevant context information and to bear in mind the social rules of interaction; thus reaching a conclusion of the story within a reasonable time frame. This is especially important for medical professionals who act under severe time constraints and who fear being overwhelmed by their patients’ narratives, if they open that Pandora’s box. This nucleus form of a narrative can emerge in a physician-patient interaction and gives the physician the specific insights as mentioned above. They can also form an element of the larger narrative evolving in the physician-patient-encounter.

Cocreation of Illness Narratives

Concerning the cocreation of the patient’s illness narrative we agree in that his/her illness narrative is formed and changed by the medical encounter (cocreation) and that this accounts for its therapeutic potential. Nevertheless, this process of cocreation in the encounter does not lead to a more or less stable narrative shared by both and recounted as such by the patient. Instead, his/her illness narrative is in the process of forming/changing through time and will be a separate form of narrative—distinct from the physician’s narrative and the narrative of the encounter, although influenced by both. Likewise the physician’s story of that patient’s illness is changed by the encounter and, in consequence, can inform the

physician's understanding of that disease—the above mentioned narrative structure of medical knowledge.¹ The patient-, physician- and the encounter narrative each signify a specific type or aspect of an illness narrative, their mutual influence is always given.

Medical professionals are trained in medical history-taking with the goal of eliciting the relevant medical facts from patients without too much “useless” information. However, allowing a narrative flow in the consultation does not necessarily require a lot of time. A study about spontaneous talking time of patients in general practice points out that two minutes of listening is enough for 80% of the patients to recount their concerns. Out of 335 patients only 7 needed more than 5 minutes. The physicians of the study were trained in *active listening*, and the study cohort consisted of many *difficult* patients with complex medical histories.²⁷ “One of the most difficult tasks in health care,” John Launer states, “may be to manage each consultation so that it continually meets both narrative and normative requirements.”²⁰ Illness narratives provide context for physiologic symptoms and results of diagnostic texts—but an illness has meaning in the biographic context of a patient. This meaning, however, must be decoded.

The Analysis of Meaning

Medicine has no respective theory or methods for analysis of meaning. It draws on the knowledge of interpretive sciences, such as humanities or social sciences. This is less a problem in research, where respective disciplines could be part of the research team, or for reading published accounts of illness, where the story is “processed” in order to convey its meaning to the reader. However, it becomes crucial in the context of medical practice—the actual physician-patient encounter. Rita Charon points out that literature and medicine classes for medical students and professionals can be a means to develop a respective sensitivity towards meaning-creating processes.^{28,29} But it might also be necessary to reflect on actual daily practice to get a feel for “narrative in action,” for example by analyzing video- or audio-recorded consultations together in a peer group. We tested that in a research project with general practitioners. In a monthly quality circle (peer review group), and additional workshops, the participants were trained in analytical methods derived from the social sciences; they then used these skills and methods to discuss recorded consultations from their own practice.³⁰ This training helped them to identify

areas of strength and weakness in their relations with patients. In addition, it had the effect of self reflection *with regard to* daily practice, and *during* daily practice, and helped to overcome established, hindering habits. After two years they reported a higher sensitivity for biographic context, subjective illness categories, and meaning-creating processes by the patient. It became apparent, however, that a narrative approach cannot be learned in a short course conveying a toolbox of narrative techniques. Changing from a conventional form of practice toward a narrative-oriented one asks for perseverance, vigilance against old routines and constant (self) reflection—ideally in a peer group with regular, video-documented case discussions.

Understanding the often-complicated and contradictory stories of suffering is not easy or self-explaining. As Rita Charon explains: “Pain, suffering, worry, anguish, the sense of something just not being right: these are very hard to nail down in words, and so patients have very demanding ‘telling’ tasks while physicians have very demanding ‘listening’ tasks.”³¹ Apart from analytical skills to understand the implicit meaning in narratives, listening skills are vital for narrative practice. The necessary listening skills go beyond specific techniques. What is needed is a particular mindset of inner involvement or, as Arthur Kleinman calls it, a stance of “empathetic witnessing”³² and an all-encompassing attention: “Attention may be the most urgent goal in our work,” Rita Charon concludes, “to attend gravely, silently, absorbing oceanically that which the other says, connotes, displays, performs, and means.”³¹

The Healing Potential of Narratives

“... [I]llness is terrible but, with some luck, it can also be full of wonders,” Arthur W Frank is convinced. “The terrors assault us at once; the wonders take longer to become visible. Stories help us gain some distance from the terrors and learn to perceive the wonders In telling all kinds of stories, we find healing.”³³ Thus, narratives can have a healing effect—both in listening to the stories of others and in telling one's own story.³⁴ Concrete evidence for this has been given especially in writing about illness and traumatic events.^{35,36} Hatem and Rider, for example, cite clinical studies that show significant changes in physiologic parameters, such as improve-

... the physician's story of a patient's illness is changed by the encounter and, in consequence, can inform the physician's understanding of that disease ...

ment of lung functions in asthma patients or decline of disease activity in patients with rheumatic arthritis due to writing about personal stressful experiences.³⁷ Another study gives evidence about an increased immune response in Hepatitis B vaccinations in a group of medical students that wrote about a traumatic experience shortly before receiving the vaccination.³⁸ Also talking about one's experience has the potential to heal, as Pennebaker makes clear,³⁹ because the expression of emotion can have a cathartic effect.⁴⁰ And it ultimately helps all parties involved in developing their human potential: "narrative-based medicine is about helping people to tell stories that have to be told if all of us are to remain fully human." Arthur W Frank concludes.^{41p1}

A study about spontaneous talking time of patients in general practice points out that two minutes of listening is enough for 80% of the patients to recount their concerns.

Narrative in Medical Practice

A narrative approach in medicine will only succeed if ultimately it has a positive effect on daily practice instead of just adding to already existing pressure. Thus, it is helpful to point out that complex illness narratives as published in biographies or collected by social

scientists are useful for training and research purposes. The complexity of these published narratives is neither applicable nor necessary in daily medical practice.⁴¹ A narrative approach in daily medical encounters consists mainly of a specific openness towards patients and their narratives in the practice of medicine, using narrative skills, such as:

- Sensitivity for the context of the illness experience and the patient-centered perspective
- Establishing a diagnosis in an individual context, instead of merely in the context of a systematic description of the disease and its etiology
- Narrative communication skills, such as exploring differences and connections, hypothesizing, strategizing, sharing power, reflection active listening, and circular questioning (a technique originally from systemic family therapy aiming at a differentiated view on a specific topic; it can include questions that are ranking, speculative, relational or contextualizing)^{41p39-41}
- Self-reflection.

To use the potential of narratives for self-reflection and professional development, Gillie Bolton proposes reflective writing courses, where practitioners put their

experience in words—even poetry—and reflect on them in a facilitated and mentored peer group.^{42,43}

Because the language and *life-world* of patients and physicians can be so far apart, it might be helpful to have an intermediary. Celia Engel Bandman encapsulates this position in her concept of a facilitator between the physician's and the patient's world that she calls a medical humanist.⁴¹ The term is derived from the philosophical tradition and worldview of humanism and is not to be confused with the field of the medical humanities. Ms Bandman's role as a Medical Humanist in a cancer center in Vermont is to create a bridge between physician and patient:

"By recognizing that the language of medicine and the language of the patient's world transformed by illness are not the same, the medical humanist creates a communication bridge. And in so doing, provides support to both doctor and patient as they face uncertainty."⁴⁴

Ms Bandman, a writer who understands the impact of words and how language shapes experience, does this, for example, by helping patients to find words for their experience and to include them in the medical record: "The 'Medical Humanist's Note' documented the patient's story in their own words and was filed alongside the clinical record which made for the whole story" (Celia Engel Bandman, personal communication, 2003 Mar 23).^{a,42}

Pitfalls of Narrative-Based Medicine

Finally, some warning remarks might be appropriate. NBM is not all beer and skittles. It takes time and effort because "significant technical and attitudinal change that is necessary does not come quickly."^{41p180} At the beginning, embarking on the narrative adventure can lead through a phase of destabilization and doubt about one's own approach to medical practice. It can also lead to a phase of getting carried away by it. "The biggest challenge in taking a narrative approach is knowing when to stop. Disease, disability, deprivation, and death are not stories. They are facts. Professionals, who get carried away by narrative ideas to the point where they forget this, are not safe."^{41p6} Narrative is not the only thing that counts in medicine: by no means is it meant to devalue medical knowledge. Also there are patients who are not interested in telling their story or sharing their innermost feelings, and not every topic raised in a consultation calls for detailed narrative exploration.

The insight into the potential of narratives is not new, but it is necessary to re-enliven it: to find ways

and forms to share stories and the personal experience of being ill and caring for the ill, and thus make a contribution to humanizing health care and encouraging individual personal growth, for the patients, the caregivers, and those who are still healthy. ❖

^a Celia Engel Bandman, founder of the Centre for Communication in Medicine, Bennington, VT.

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Respect

Their story, yours and mine—it's what we carry
with us on this trip we take, and we owe it to each
other to respect our stories and learn from them.

—William Carlos Williams, 1883-1963, physician and poet