

Original Article

The Role of Clinical Records in Narrative Medicine: A Discourse of Message

John W Murphy, PhD; Jung Min Choi, PhD; Martin Cadeiras, MD

Perm J 2016 Spring;20(2):103-108

<http://dx.doi.org/10.7812/TPP/15-101>

ABSTRACT

This article is designed to unite theory and practice. The focus of attention is the impact of narrative medicine on clinical records. Specifically important is that records are created through dialogue, whereby patients are able to grow the record through their ability to offer critiques and alternative explanations. Merely allowing patients to peruse their records, through advances in technology, is not sufficient to facilitate this aim. Various theoretical and practical considerations are discussed that may facilitate patient involvement and the creation of more accurate and relevant patient records.

INTRODUCTION

Narrative medicine has become a recognizable theme in the medical literature nowadays. In the most general terms, this development represents a critique of the medical model.¹ But this trend does more than simply raise the issue that standard medical practice is reductionistic. The point, however, is not to become merely more holistic and to consult increasing amounts of data when making clinical decisions. Within the framework of narrative medicine, additional data do not necessarily result in interventions that are more attuned to the histories and daily lives of patients.

Rather than asking for more data, the nature of knowledge is called into question. In this regard, those who promote narrative medicine advance an epistemology that is not pursued regularly by those who critique reductionism. Specifically, owing to the emphasis placed on language use, a serious question is posed about the nature of both physical and social reality. A desire for more data, accordingly, does not require reflection on how knowledge is generated and used.

At the core of narrative medicine is a new perspective on how knowledge

gains legitimacy.² What constitutes valid knowledge is related to human action, specifically how language is employed. The basic idea is that the reality of patients is never directly encountered by a clinician, or anyone else, but is revealed gradually through the stories they tell about their lives and social conditions. Any so-called markers of illness, therefore, should not be treated as objective signs but codes because their identity is snared in layers of culture and the accompanying interpretations.

The accumulation of information about a patient is thus a hermeneutic exercise.³ Instead of trying to unearth facts, those who practice narrative medicine attempt to unravel the meaning of those facts. Symptoms, accordingly, should be not merely documented but situated within the stories patients weave to make sense of their lives. How these patients interpret and organize their lives, including their illnesses, is the focus of attention.

Although critics of narrative medicine view this theory to be dense, they also cite the paucity of concrete examples of how this linguistic philosophy changes clinical practice.⁴ Additionally, at times, the theory and practice seem to be

worlds apart. Hence, the thrust of this article is to apply narrative medicine to a particular practice, specifically clinical record keeping, to make clear the impact of this epistemology.

THE LINGUISTIC TURN

Narrative medicine is tied intimately to the so-called linguistic turn, that is, the theoretical maneuver that identifies language as instrumental to how behavior or events are perceived.⁵ Those who accept this philosophical maneuver want to change the way in which language is often described. In traditional parlance, language is identified as a tool. Accompanying this outlook is the assumption that the influence of language can be overcome, thereby revealing an objective reality. According to Roland Barthes, a French literary critic, there is thought to be an outside to language that can be reached with the proper methodology.⁶

This description supports a principle that pervades Western philosophy. That is, truth can be discovered only if human contingency is transcended, so that external principles can be grasped. In this particular case, language is envisioned to be a pointer that can note crucial distinctions and highlight various aspects of the world. All the while, however, the objects of these activities are not influenced by language. Their objective features are simply put on display. This perspective is called the indexical thesis.⁷

Beginning with Wittgenstein, but enhanced by a host of writers such as Merleau-Ponty and Lyotard, many philosophers began to reject this theory.⁵ Their contention is that language is not neutral, like a pointer, but mediates

John W Murphy, PhD, is a Professor of Sociology at the University of Miami in Coral Gables, FL. E-mail: j.murphy@miami.edu. Jung Min Choi, PhD, is a Professor of Sociology at San Diego State University in CA. E-mail: jchoi@mail.sdsu.edu. Martin Cadeiras, MD, is a Professor of Medicine at the University of California, Los Angeles David Geffen School of Medicine. E-mail: mcadeiras@mednet.ucla.edu.

everything that is known. Persons live through language. And owing to the ubiquity of speech, including the accompanying interpretations, no facet of social existence is directly encountered. There is nothing outside of language that eludes interpretation, including the body or any other facet of illness. In this regard, interpretation is foundational.

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For this reason, Wittgenstein inaugurated the trend of referring to language as a game.⁸ The idea behind this new metaphor is that persons are immersed in language, and their speech acts shape reality. How they play the game, in other words, provides their lives with organization and meaning. Language does not merely represent reality but is creative and inventive.⁹ As a result, as phenomenologists say, now facts must be

understood to have a “biography” that physicians must consult, if they are going to understand accurately a patient’s condition.¹⁰

Arthur Kleinman, an aficionado of patient stories, argues that a moral world is the product of language use.^{11,12} Physicians must learn how to enter this domain to make a sound diagnosis and outline a sensible course of treatment. What is often acknowledged at this juncture, given the importance of these narratives, is that physicians should learn how to listen to their patients. Although that is a valuable lesson, narrative medicine moves beyond simple listening.

Listening is linked typically to exhibiting empathy or care, or extending comfort. In the end, the aim is to become more patient-centered. The problem with these traits, from the perspective of narrative medicine, is that they do not necessarily involve the co-creation of knowledge. All that may occur is that the physician is attentive to more details.

So what is important about co-creation? As opposed to monitoring details, co-creation entails recognizing that patients interpret these features, and accuracy is achieved only by infiltrating these interpretations. Rather than comprised

of empirical traits, a patient’s world is an ongoing construction, undertaken with a variety of persons, including physicians, and may not be easy to enter. After all, empirical markers are neat, whereas interpretations are murky, ambiguous, and difficult to pin down. The question that becomes important is: how can the medical record facilitate entry into this elusive domain?

What is important to note is that patients always present an illness; this condition is revealed gradually and, often, circuitously by a patient.¹³ When judged by narrative medicine, however, this process is not disinterested but includes perspectives, values, and commitments. A presentation is always motivated and expresses an angle or disposition. Nothing can remove symptoms from these entanglements, even the most sophisticated laboratory tests. Furthermore, how a presentation will progress or be received is difficult to predict.

A physician, consequently, must learn how to read these scripts in a relevant manner. To fulfill this task, the standard approach to medicine must be rethought, whereby clinicians focus primarily on the empirical features of a case. To make this shift successfully, how persons construct their worlds must be elevated in importance and incorporated into a clinical record. A key principle at this juncture is that data have specific significance for patients.

BEYOND DOCUMENTATION: AN ARCHAEOLOGIST’S TOOL

The traditional purpose of the medical record is to document a patient’s condition. These data that are gathered are thought to enhance the decision making of physicians and other clinical staff. The problem with this scenario is that patients present their situation. As a result, data are not easily observed but enmeshed in perspectives, conflicting interests, and habits. Owing to these influences, some critics argue that symptoms are negotiated.¹⁴

Through a process of give and take, certain ailments emerge as paramount and are given meaning.¹⁵ And if the physician is skilled at this dialogue, a proper assessment is made of these complaints.

Within the common purpose of record keeping, a problem list is established. Care must be taken to ensure that this catalogue corresponds to what is expressed by patients, rather than cultural stereotypes or other commonly held or clinical expectations.

But in principle, documentation is expected to be dispassionate and outside of this exchange.¹⁶ Documentation, accordingly, is focused, attentive, and precise. Those who document properly, in fact, are taught to reflect or mimic the condition presented by a patient, in the most detailed manner possible.¹⁷ If undertaken properly, documentation is hardly an inspired activity. Regularity and standardization are anathema to the active engagement of a patient.

As should be noted, documentation is inconsistent with narrative medicine. For example, classifying and categorizing are presumed to be precise, and therefore are outside of the exchanges that are a part of any negotiation. But the thrust of narrative medicine is not to piece together tidy bits of data to solve a puzzle. In other words, physicians should not strive to be data processors who covet clean input to make decisions that mimic a logic-tree.

Rather, to borrow from Foucault, physicians should be “archaeologists.”¹⁸ According to this writer, what does an archaeologist do? As the term suggests, they get to the base or root of behavior or events. What Foucault elevates in importance, however, is the discursive or linguistic practices that are obscured by empirical traits but hold the key to their meaning or significance.¹⁹ Archaeologists explore this vital domain that remains hidden when empirical data are pursued. They delve into recesses that are interpretive and thought traditionally to impede sound clinical decision making and thus dismissed as risky.

The challenge that remains is how to transform the medical record into the archaeologists’ tool. How can this device be rethought, so that classification is eclipsed by entry into a realm that is often eschewed? In the next section, some themes will be addressed that can provide a new slant on record keeping that stresses the meaning of physical traits. The hope

is that by recognizing some important distinctions, the hermeneutic task emphasized by narrative medicine can be incorporated into record keeping.

RELEVANT INFORMATION: MESSAGE

The term *hermeneutic* is derived from the name Hermes, the messenger god.³ The basic idea is that in every physician-patient exchange a message is at stake. Without a story, in short, data are useless. Like Hermes, those who practice hermeneutics are attuned to messages. What is required, to paraphrase Barthes, is a culturally or socially appropriate reading of texts.²⁰ Physicians, in this regard, must learn how to read in the manner intended by authors (who, in this discussion, are their patients). The point of making the following distinctions is to prompt an awareness that messages hang in the balance of every interaction between a physician and patient.

Körper vs Leib

Owing to the pervasiveness of language, and thus interpretation, the practitioners of narrative medicine recognize that patients do not have bodies. In this sense, they borrow a differentiation made by phenomenologists between the *Körper* and *Leib*.²¹

The term *Körper* is adopted to characterize the usual view of the body. That is, a bodily existence is primarily physiologic. Even in more holistic approaches, where the body and mind are thought to interact, primacy is still given to physiology, although this connection may make an intervention complicated. Still, in the end, physiology is not understood to convey a message, other than those linked to nature.

A *Leib*, on the other hand, is never treated as such an objective entity. According to this rendition of the body, the dualism that sustains a *Körper* is illegitimate; interpretation, as Stanley Fish suggests, goes all the way down, even to physiology.⁷ As a result, even the body is inundated by cultural messages. Anthropologists have coined the phrase “local biology” to capture this association.²²

Those who pay attention to physiology will likely miss this interpretive dimension. For example, clinicians who

use the body mass index to calculate a person’s appropriate weight can fall into this trap. Whether a person is considered to be overweight is based on various physical dimensions. Although critics have noted the reductionism that is operative, the validity of interpretation is often downplayed or ignored.²³ Specifically, a person’s body image may be inconsistent with these measurements, and thus s/he may engage in a range of activities, including sports, that is indicative of a healthy lifestyle. The label overweight, accordingly, may be inappropriate and encourage behavioral changes that are harmful.

In narrative medicine, persons do not have bodies, as noted originally by Gabriel Marcel, because they are not things.²⁴ Bodies are not objects that are possessed and that physicians probe, but are lived and closely tied to images, myths, and logics about bodily functions and care that may contradict the focus of traditional medicine. Accordingly, a message may be written by the body that physicians are unprepared to read correctly.²⁵

From Context to the Life-World

A key facet of a medical record is to provide background information on a patient. Given the significance of messages, even those conveyed by physiology, this function is especially important in narrative medicine. This history can offer insight into the daily lives of patients, related, for example, to their environment and relationships. A somewhat holistic, and thus relevant, picture of a patient’s life can be made available.

But true holism will be forthcoming only if a difference is recognized between context and life-world (*lebenswelt*). Typically, a comprehensive medical record supplies a social or psychological context for a patient’s ailments. In narrative medicine, however, a context may not be the framework that should be sought.

What is wrong with context? Most often, context takes the form of additional data. A psychological or psychosocial report is often introduced at this juncture, so that an array of information is available about a patient’s job, educational level, or family situation. The problem,

however, is that these data may simply describe surrounding conditions. The context that is supplied, in other words, may be treated as supplementary input, derived from the objective features of the environment. No messages may be involved in this collateral data.

As a result, those who adhere to narrative medicine make a startling maneuver and ignore context! Nonetheless, the holism that they desire requires that illness behavior be existentially situated, or a patient’s presenting problem will not be correctly understood. As a result, again related to phenomenology, context is now treated as the *lebenswelt*.¹⁶

A patient’s life-world is replete with interpretation and alive with meaning, instead of filled with dead or lifeless empirical indicators. The aim of the medical record, accordingly, is not to document the presence or absence of specific objective traits but to read the messages that emanate from this realm.

Take high blood pressure as an example. Clearly, stress can lead to this condition. But research shows that stress is not necessarily related to obvious social conditions.²⁶ Identical empirical events may be interpreted very differently, thereby resulting in unique responses. The message that is present, and must be read appropriately, pertains to the meaning of stress and the personal and interpersonal interpretations of this situation. In terms of the life-world, the usual portrayal that stress leads to anything, including high blood pressure, omits a crucial factor. Specifically, the factors that spawn stress are joined together through experience, rather than by a natural, empirical link.

Messages have story lines that connect events to each other.²⁷ This relationship may not be causal in the traditional sense—with “A” and “B” identified clearly and structurally joined—but this interpretive bond is sufficient to supply a rationale for outcomes. A storyline must be read properly, however, before the link can be understood properly between events, social or natural, and a physical condition. How patients envision this association can help to unravel the responses that lead to many physical problems.

No Message to “Markers”

The use of the term *markers* gained prominence during the early 1980s. These markers, sometimes known as biomarkers, are often defined as objective, measurable characteristics that are indicative of normal or pathologic conditions.²⁸ Prostate-specific antigen and matrix metalloproteinases, for example, have been used to make judgments about the prospects of experiencing the onset of cancer. Furthermore, owing to their empiric character, in addition to monitoring physiologic states, biomarkers are thought to improve the assessment of health risks.

At this time, and consistent with the emerging conservative politics, the cultural side of medicine began to be rolled back. Within this historical period, the discovery of markers was celebrated. A range of disciplines adopted this nomenclature with pride that progress may finally be witnessed in terms of identifying and remedying problems. The discovery of these markers, for example, may lead to the early detection of health issues and more effective interventions. Clear insights would be in the offing because of the availability of these reliable clues.

This elevation of markers, however, is connected to an epistemology that is antithetical to narrative medicine.²⁹ Specifically, markers bypass the usual cultural ambiguities and extend to the root of a problem. In view of these visible indicators, probabilities are reduced and desired outcomes improved; direct measurements are improved and causal pathways illuminated. What these objective signs provide is a sound shortcut to determining the presence of a problem and a successful course of preventive or remedial action. In this way, connections are made that might otherwise be mediated and diluted by various situational contingencies.

Nonetheless, a sort of tunnel vision might be encouraged by a reliance on markers. Specifically, markers can easily begin to overshadow experience; after all, these signs represent a direct, natural link to a deeper realm. With readily identifiable indicators available that promise the quick determination

of a health issue, the lure of markers is difficult to resist.

This attraction to markers is another area that depends on dualism—an index is embraced that is not confounded by cultural and other situational influences. Accordingly, there is no message to markers, but only a clear logic and the accompanying implications. Such precision would be hard to ignore. But, here again, narrative medicine encourages a bold move on the part of medical practitioners. That is, the messages of patients should not be marginalized by markers. After all, markers are codes and thus never objective.

What happens to markers in narrative medicine is that they are recognized to be codes that are inundated by experience and in need of proper deciphering. Accordingly, their message may indicate a biological condition, along with other stories that are equally noteworthy. A marker for Down syndrome, for example, may say more about a society, family members, or a school system than a future medical disability.

The point is that markers do not stand alone, like an objective referent. These codes, instead, are part of a broader social or cultural text that hermeneutics would always incorporate. The message of markers is thus unduly truncated if their interpretive character is equated with empiric regularities. When this tactic is followed, only the story of biomedicine is told. The shortcoming is that this specific script may have limited relevance to the problem at hand.

Often these distinctions are highlighted to draw attention to the difference anthropologists note between illness and sickness. Illness relates to physiology, whereas sickness is something existential.³⁰ But as should be noted, this differentiation is not stressed in narrative medicine because nothing escapes the influence of interpretation; every facet of a person's life is existential. This distinction is simply another rendition of dualism.

So, in the end, what is accomplished by a medical record? Within the frame of narrative medicine, the aim is not to simply localize a problem and streamline decision making.³¹ Such a static

image is no longer acceptable. What is required, instead, is that a problem be situated in a patient's life-world. Such a project extends beyond documentation and demands a hermeneutic project that is dynamic and engaging, and thus requires time and sensitivity.

A PATIENT'S ELUSIVE IDENTITY

As suggested earlier in this article, the critique given thus far is thought to lead to a patient-centered orientation.³² Indeed, the point seems to be that patients matter, specifically their experiential accounts. The approach encouraged by narrative medicine, in this regard, may seem quite startling. Specifically, narrative medicine is not necessarily patient centered. The reason for this decision is quite simple: There is no patient!

Although this conclusion may be fairly blunt, the rationale employed has a complex theoretical heritage. Consistent with the work of both Barthes and Foucault, persons do not have an essential identity.^{6,33} Their identity is elusive because interpretation leaves no aspect of social existence, personal or collective, unscathed. The various facets of an identity, therefore, are shaped by narratives and must be closely read.

Again, in line with Marcel's philosophy, persons do not have an existence but make their identity through personal decisions and initiatives and the actions of others.²⁷ The end result is that identities are not discovered, observed, or encountered but revealed through dialogue.³⁴ Persons define themselves, construct traits, and make choices, all of which suggest that a patient is an ongoing construction.

The term *patient centered*, however, suggests that a patient's identity has a stable foundation. Properly understanding a person, accordingly, is dependent on discovering this base and the accompanying values and principles that guide this individual. For example, Biehl, Good, and Kleinman try to elevate subjectivity, a central storehouse of data, in importance, so that patients might be treated sensitively.³⁵ But in terms of narrative medicine, such a core does not exist; looking for such a base, in fact, is a distraction. All that is available,

instead, is a myriad of stories that move an identity in one direction or another. In a manner of speaking, a patient is a moving signifier that should be sought, rather than a composite of basic traits.

RATHER THAN GATHER, INTERPRET KNOWLEDGE

Instead of patient centered, narrative medicine should be thought of as dialogue centered. In actual practice, this difference is critical: knowledge about a patient must be interpreted rather than gathered. This change is necessary because a patient is a message that must be deciphered. Through rapport, and the connections that are made, the story or stories that constitute a patient can be appreciated.

A medical record can facilitate dialogue, for example, by establishing a proper framework for relevance, using appropriate probes, situating answers, and making sure that correct language use is specified. Furthermore, an appreciation can be established for the line of reasoning a patient is constructing, so that the logic of an action or response becomes clear. A medical record can facilitate dialogue, in sum, by no longer directing interaction but by growing through the discourse that is enacted.

In this way, patients participate in the clinical record. And like any true dialogue, language use is modified and assumptions corrected until real understanding is achieved. Rather than guiding the discourse, the medical record is a product of this activity and always vulnerable to reassessment. As a result, relevant knowledge can become accessible.

This process of growing the clinical record is significantly different from what Charon refers to as patients becoming curators of this document.² Becoming a curator may mean that patients are merely allowed to peruse their records. In many care centers this activity is already encouraged. Growing the record, however, requires that patients be able to recreate the record, if necessary, to reflect their constructions of behavior or events. In the broadest sense, the record is open for challenge and revision.

The following question may arise, however, from those who work in large and busy medical centers: How can this depth be acquired in a 20-minute visit?

In emergency situations a rapid response is expected. But in many other cases narrative medicine can be practiced. Nonetheless, the patient-physician experience must be reassessed. If the focus is the life-world, a patient will be viewed differently than in the past from the first encounter, thereby altering the entire relationship. Completing a health history, for example, will be less routine and mechanical. And over time, following the adoption of this new perspective, a rich body of patient information will be accumulated.

CONCLUSION

The goal of this article is to initiate a critical discussion about the character of medical records. Perhaps a fitting conclusion is to suggest that a new image of record keeping is needed, especially from the perspective of narrative medicine. The field of technology design might have something to add at this juncture. Specifically, patient care may be improved if record keeping were guided by the principle of interface. In short, records must interface with patients.

But interface can have many meanings. Alignment and integration are two examples. Both of these tactics, however, suggest that asymmetry is present, and the process is mechanical; parts of an activity are simply thought to fit together neatly.

The interface that is needed, and consistent with narrative medicine, is much more dynamic. In this sense, the work of Lévinas is helpful.³⁶ What he adds to this discussion is that persons can meet, face-to-face, in a respectful and dignified way. Most important, persons can become integrated into one another's world. Charon, for example, calls this sort of interface "affiliation," which encompasses the "interpenetration of self and other."² This sort of adjustment represents the interface required by narrative medicine, so that messages are properly read.

The aim of projects such as OpenNotes and, perhaps in the future, OurNotes, is to facilitate the proper reading of case notes. OurNotes, especially, attempts to promote the participation of patients in the creation of their records. Simply making records available, however, will not achieve this aim.³⁷ Most important is that patients are able to shape a record through their insights, challenge a physician's assessment, and propose alternative explanations and courses of action. In other words, improved technology, along with the ability to disseminate information, is not necessarily the answer to increasing the participation of clients in their own care.

This new mode of interface, as is indicated throughout this discussion, is dialogical. The clinical record, accordingly, grows out of a discourse that reveals worlds, rather than a range of evidence, and is truly inclusive. Combined with the other points raised in this article, the introduction of this new imagery may elevate in importance a patient's life-world. After all, true interface embodies this intimacy and requires dialogue.

But as is suggested through this article, dialogue does not occur automatically by simply talking about this activity. And in the case of these two computer programs (OpenNotes and OurNotes), the introduction of such technology may not produce this result. After all, dialogue is a human rather than a technical process. Patients, who may be afraid of interacting with physicians, will have to be encouraged to make suggestions and voice opinions, whereas physicians will have to adopt a new image of their patients. Nonetheless, dialogue is rarely impossible but must be viewed as worthwhile, and truly pursued, if important changes required by narrative medicine are going to occur. ❖

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Disclosure Statement

The author(s) have no conflicts of interest to disclose.

Acknowledgment

Mary Corrado, ELS, provided editorial assistance.

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Different

Taking care of patients is different from taking care of disease.

— Eugene A Stead, Jr, MD, 1908-2005, medical educator, researcher, and founder of the Physician Assistant profession