ABSTRACT

The thrust of narrative medicine is that patients and communities construct stories that guide their lives and give meaning to both health and illness. The responsibility of health care practitioners, therefore, is to learn how to read these local narratives to provide care that is relevant to an individual or community. Given the recognition that interaction must be tailored to the subjective experiences of patients and their communities, can there be universal ethical standards in the treatment of illness? We argue that the constructed nature of patient experiences does not pose a threat to making ethical clinical judgments. The solution to this dilemma requires that the traditional distinction between objectivity and subjectivity be eschewed by clinicians in favor of establishing dialogue with patients. Narratives are never created alone and are therefore not esoteric. Listening carefully to patients’ stories is an ethical practice that can be fostered in health care settings. Subjectivity can be embraced by clinicians without jeopardizing ethical or evidence-based patient care.

INTRODUCTION

Narratives have become increasingly important in a variety of areas such as psychology, philosophy, and literary criticism. Narrative medicine also has become an important topic. The point of this trend, in general, is that the delivery of health services should become more holistic and sensitive to the claims of patients. In contrast to the traditional biomedical model, physiology should become more holistic and sensitive to the claims of patients. Advocates of narrative-based care claim that in the absence of individual and collective biographies, biomarkers and other facets of physiology have little importance.

This trend is compatible with the philosophy behind the Community Mental Health Act of 1963, not to mention the growth of community health centers that began a few years later. After this legislation, services were supposed to be offered in the “least restrictive environment,” which usually means the community. Although there were major challenges to realizing community-based care without dedicated funding streams, some of which never became available, community health centers today make a full range of outpatient and preventive services available, including limited inpatient care. The aim of providing care in community settings is to ensure that services are attuned to local norms, with regular input from patients, community advocates, and other nonmedical people to provide a holistic, multidisciplinary vision of how treatment should proceed. Today, this influence can be seen most clearly by the inclusion of patients and residents on health centers’ boards of directors, of which laypeople must comprise a majority.

The narratives that are provided by these patients and residents about health and illness frame behavior and events and provide biomedical data with meaning. For example, what is meant by illness or mental illness is revealed in the narratives that patients bring to the medical encounter. The importance of these narratives for everyday medical practice is that services can be made more relevant on the basis of how patients and communities interpret themselves and their situations. The goal is to engage patient stories so that this information can be used to improve the effectiveness of a therapeutic intervention. And although clinicians are limited in the time that they are able to spend with patients, there are opportunities to engage patients’ stories in various parts of the standard medical interview; even amid a hectic schedule, the principles of narrative medicine can be adopted to improve communication with patients.

Narrative-based care is part of a larger movement that tries to elevate the dignity of individuals and communities. The idea is that no longer should medical professionals or other caregivers dominate service delivery. In narrative medicine, what patients have to say is vital not only to providing patient-centered care but also in arriving at a sound diagnosis and effective treatment plan. Clinicians, for example, should not ignore the histories of patients’ communities, personal backgrounds, and pertinent cultures during the medical encounter. For this reason, Engel made his famous call for a biopsychosocial model of health care. Engel’s point is that a proper evaluation of health status should be broad, reach beyond physical elements, and include how patients feel about themselves and understand their environments.

Medical and social services, in other words, should be attuned to the “world” that is enacted in a community. A world is simply the frame of reference that is defined by patients—a realm of living composed of a stock of relevant knowledge, customs, and practices. World entry, therefore, allows practitioners to understand how patients interpret behaviors, so that relevant therapeutic interventions can be provided. The big idea is that through the incorporation of knowledge specific to a patient’s world, clinical judgments will not violate the values of individuals or communities.

However, a problem is thought to arise at this juncture. Given the influence of patients and their perspectives, can ethical judgments still be made? Without the usual objective and universal standards that underlie much of biomedicine, some critics fear that norms will proliferate without any basis to substantiate

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ethical claims. The relativism introduced by integrating individual patient stories might threaten clinicians’ ability to identify ethical principles that are relevant across a diverse patient panel. A focus on narratives, however, does not signal automatically the onset of a cacophony of claims that cannot be reconciled. Quite the opposite, because neither personal nor collective narratives are created alone, a framework for ethics is available that is alive and practical. The purpose of this article is to lay the groundwork for this strategy. Through a discussion of the philosophical background of traditional and narrative ethics, we will provide a number of examples to elucidate how clinicians can adopt ethical strategies while at the same time promote the general principles of narrative medicine in their practice.

In clinical settings, people can treat one another with dignity in the absence of grand moral imperatives. Zaner argues, for example, that principlist ethics—rooted in universal rules or laws of decision making—are not necessarily helpful in sorting out how patients and clinicians should interact. The standard critique of principlism includes a wise call for clinicians to be pragmatic, avoid universal rules, and deal with concrete problems. Nonethe-


tless, while avoiding abstractions, problems can still be treated in a naturalistic manner, as examples of standard cases. In line with the thesis of this article, that narrative ethics can be integrated into everyday practice, practitioners are encouraged to move away from abstract rules when making clinical judgments and engage the worlds created by their patients and communities.

**DISCUSSION**

**Philosophical Background**

This “narrative turn” raises interpretation and human agency in importance. In this regard, the usual Cartesian dualism that is operative in health care, particularly biologically focused interventions, is subverted. What dualism means in the health context is that interpretation (subjectivity) and the body are thought to occupy different realms, and thus the body can be treated as a thing or object that can be observed impartially. Subjectivity, by contrast, has been ignored traditionally because this element was deemed unhelpful or potentially disruptive to producing an objective diagnosis and carrying out an appropriate treatment plan. Narrative medicine, however, treats dualism as defunct. If narratives and interpretation inundate everything that is known, subjectivity should no longer be separated categorically from objectivity, so that patient physiology can be readily isolated and serve as a reliable source of knowledge for clinical decision making.

The traditional pursuit of objectivity that has substantiated the biomedical model relies heavily on the ability to isolate patient experiences and any influence of subjective interpretation. Dualism, in fact, is the centerpiece of biomedicine. With the undesirable effects of individual interpretation minimized by focusing on objectivity, proponents argue that reliable clinical procedures can be established. But the narrative turn compromises this outlook because interpretation is pervasive and unavoidable in any human interaction. Following the narrative turn in philosophy, any claims that interpretation should simply be avoided are difficult to accept.

One outcome of this antidualist maneuver made in narrative medicine is that a patient’s or community’s worldview becomes important. Patient experiences become relevant when behavior or events are understood to be filtered through language rather than simply objective—an extension and deepening of the earlier Sapir-Whorf hypothesis. Rather than self-standing, facts presented by patients are framed by language and given significance. As a result, health and illness, for example, have meaning constituted by individuals and communities that cannot simply be measured empirically. For this reason, personal or collective narratives become vital in comprehending both illness and wellness correctly.

In the absence of dualism, physiologic and other traditional objective indicators must be viewed as signs that require interpretation. As Frank argues, devoid of interpretation, data such as symptoms are things that say little or nothing. Making a diagnosis, accordingly, is an interpretive process, whereby the attempt is made to understand individual or collective narratives in their own terms. “Narrative competence,” the ability to read patients’ stories accurately, is thereby essential to unearthing relevant knowledge about a case or problem. In this regard, Mishler writes that the “voice of medicine” should not be allowed to overshadow the voices of patients or communities. Because every piece of data is embedded in a story, facts should be interpreted according to a relevant storyline if they are going to be properly understood. The problem with Mishler’s work, however, is that he does not formulate a philosophy of language that informs his advice.

In view of this narrative outlook, people should not be thought of as simply having a disease or other problem, similar to a possession. This portrayal is inadequate because they are always interpreting a malady. This realization has shaped the more recent move toward first-person language in medicine to remind clinicians that patients are more than just a disease. Epileptics are more properly referred to as patients with epilepsy, for example. Rather than encountered, any illness is situated in a patient’s world; problems are therefore related to a myriad of claims, perspectives, and unrelenting interpretations. As clinicians say, every problem is presented and thus always shaped in one way or another by a patient’s experience.

Some critics consider critiques of objectivity a well-worn topic in discussions of health care. But the position advanced by narrative medicine goes beyond the usual criticism that values and facts are related or that knowledge is enmeshed in the patient-physician relationship. There is no doubt that in these viewpoints, positivism, or the reliance on objectivity, is called into question. The influence of dualism in medical practice, however, is not so easily overcome. In these formulations, facts tend to still exist alongside values in the clinician-patient interaction.

A proper reading of narratives, on the other hand, is not equivalent to a close or sensitive examination of facts. Even viewing values as supplemental to facts is insufficient. Indeed, facts do not exist outside the frame provided by narratives. An adequate reading requires that the personal or collective world created by these stories be appreciated. As will be discussed later, this issue is at the crux of narrative ethics.
Critique of Objective-Based Interventions

Clinical interventions based on biomedicine are supported by dualism, and thus objective features are presumed to be available to guide clinical judgments. Physiologic properties, for instance, are thought to provide brute data that serve as reliable indicators of a health problem.\textsuperscript{35} In the face of dualism, remember that the body is an object available for investigation.

Not all interventions are connected directly to physiology. Often more social considerations are involved in clinical assessments. At the core of these evaluations are so-called social indicators, such as demographic or economic features, that are also treated as objective.\textsuperscript{34} As opposed to physiology, however, these elements are clearly cultural and reflect various norms and behavioral traits. Anxiety, for example, is not initiated by empirical properties but presupposes difficulty interacting effectively in different contexts and with various people.

The issue that must be addressed when moving into this social arena is that individual or collective reactions should be expected. Let’s take seriously the example of anxiety. People experience anxiety in a specific situation, instead of in some free-floating manner.\textsuperscript{35} They are always interpreting symptoms of anxiety, rather than simply experiencing them and reacting accordingly. As a result, identical environmental conditions might provoke entirely different reactions: Anxiety in some individuals or groups and anger in others. In this sense, people do not respond in a knee-jerk manner to events but frame conditions in often idiosyncratic ways.

If these situations are going to be treated as objective, a method must be used to tabulate and classify social indicators that avoids interpretation. Poor housing and overcrowding, which are often presumed to be objective features, are often linked to conditions such as anxiety. These data are often introduced into the clinical record as social determinants of behavior without any mention that they have cultural significance and local meaning.\textsuperscript{36} What bad housing means is not necessarily obvious or a universal designation. This determination, in narrative discourse, requires that the biography of a person or community be grasped.

At this clinical juncture is where devices such as the Diagnostic and Statistical Manual of Disorders, Fifth Edition or other “expert systems” are considered helpful in biomedicine.\textsuperscript{37,38} By using logic trees to gather and evaluate evidence, the image can be created that judgments are mechanical. One critic has referred to this process as indicative of “cookbook medicine.”\textsuperscript{39} The point is that recipes are not usually thought to involve interpretation. Formalized rules are simply followed until a final clinical decision is reached. The assumption is that logic is clear and devoid of any bias. The clinical judgments that are produced are thought to be impartial and unaffected by clinicians or anyone else. Clearly, such an approach that relies on objectivity is insufficient for understanding the complex relationship between patients’ backgrounds and their illness progression.

But what about diseases such as HIV/AIDS that seem to be linked firmly to physiology?\textsuperscript{40} Is interpretation still relevant? In the early years of AIDS activism in the 1980s, many people who had this disease began to question the basic truths of medicine, along with medical experts.\textsuperscript{41} These people believed that the experiences of those with AIDS were being overlooked, and thus certain key insights and connections were being missed. Because of the involvement of these laypeople, perceptions of AIDS changed in the medical community and new procedures and drug trials were conducted. The point is that knowledge outside the medical arena proved to be valuable in dealing with this illness. Local interpretations of this condition mattered and framed this disease in ways that were important to a particular community of individuals who were experiencing illness.

Consider also how narratives play into the issue of disabilities. In the field of disability studies, a movement appeared in the 1970s that rejected the biomedical model.\textsuperscript{42} This perspective, critics believed, was reductionistic because people with disabilities were treated as little more than physical objects. Therefore, the “social model” was offered as a replacement.\textsuperscript{43} Many changes were suggested, but most important for this discussion is that people’s disabilities are framed or shaped by their values, ambitions, commitments, and so forth. In short, they should not be judged by some objective, able-bodied assessment of their physical or mental abilities.

In each of these examples, objective physiologic or social indicators provide little insight into the lived character of a physical or mental illness. How these phenomena are personally and interpersonally navigated, and thus experienced, is overlooked. Whether an intervention is needed or appropriate is a matter of educated guesswork because the experiential worlds of people are ignored. What patients understand to be a problem, including their responses to situations, is obscured by professional nomenclature and theory. Yet these sources of bias are seldom recognized as harmful.

These criticisms of objectivity, however, are often taken seriously by clinicians who aim to connect with their patients and provide effective care. Indeed, many acknowledge that health care services should be patient-centered and thus culturally attuned.\textsuperscript{42,43} On the other hand, there may be a downside to this thinking. Specifically, does the move away from objectivity complicate efforts to develop guidelines that can be applied when dealing with diverse individuals or groups? By focusing interventions in a social and cultural way, and avoiding generalizations, ethical standards may be compromised. If narratives are unique and defy classificatory schemes, can ethical judgments be made about how treatments should proceed? The usual assumption seems to be that without an objective foundation, reliable judgments are difficult to sustain. This conclusion, however, reflects a tradition in which ethical standards are expected to be unaffected by interpretation and other sources of human caprice.

An Earthly Ethic

The traditional universal ground of ethics is obscured by the narrative turn. However, according to Marx,\textsuperscript{44} this trend in philosophy, and the associated pervasiveness of interpretation, does not necessarily spell the end of ethics. In fact, he contends that ethics without the usual universals and abstract exemplars is possible. He refers to this option as an “earthly” ethics. Marx uses this term specifically within the framework of existentialist philosophy. Consistent with this philosophy, he is making the
point that all norms and values are invented by individuals in relationship to their communities. These values are reinforced and gain legitimacy through everyday interaction. The result is that the only possible origin of ethics are the activities whereby people interpret their surroundings and struggle to make sense of their lives.

Fundamental to this new ethics is that everything is affected by the attempts of people to make their lives meaningful, particularly the narratives they tell about themselves and others. There is no God’s-eye view, or perch, that can supply a timeless referent for ethical judgments, because every standard is enmeshed in interpretation and the related contingencies. The alternative is that ethics must begin and end from where people are located, that is, their daily existence with others. As a result, ethics must be conceived horizontally rather than vertically, or at the nexus of what Buber calls “genuine meeting” between people.

What is this place like where meeting is possible? The most obvious trait is that people do not exist independently; narratives are thus never written alone. In the words of Lévinas, people always exist “face-to-face” and are embedded in this interaction. Daily existence, in this sense, is thoroughly intersubjective and united through discourse; thus, nothing objective is either available or required to unite people or judge ethical behavior.

*Intersubjectivity* is a term popularized by phenomenologists and some existentialists. Their aim of introducing this concept is to counteract the then prevailing scheme that treats people as individuals who are categorically separate from one another. Perhaps a “community of discourse” is the best way to characterize this intersubjectivity. But discourses would be more accurate. After all, several narratives are present regularly that overlap and sometimes come into conflict.

Despite this proximity and the ability to interact, people never merely confront one another. For interaction to take place, individuals and communities must learn to read one another successfully. They must engage one another through their respective narratives, so that they are “in tune.” Ethical principles, accordingly, must reflect this sort of interpretive, iterative connection.

An ethic mediated by interpretation is operative in this situation. Specifically, individuals and communities must be able to read others in their own terms. The new imperative is to listen, reflect, and enter the worlds of others. The argument is not to prescribe how listening should be codified, as a specific moral imperative or set of rules, but to let the stories of others be expressed and properly situated. Narrative ethics requires that people read and adjust to one another, including their respective situations, and establish mutually respectful bonds. Hence, ethics begins with local narratives that specify how interaction should proceed.

Ethics is thus dialogical. Individuals or communities are treated properly when their respective stories are read as intended, rather than distorted by the extraneous narratives often introduced by clinicians and their diagnostic devices. For example, when a clinician uses a diagnostic narrative unrelated to how patients construct their lives—through the use of a fixed health checklist or assessment instrument—this principle is violated. A precise judgment may be rendered, one that stems from following specific rules and standards but is irrelevant and possibly damaging.

A diagnostic checklist, for example, tends to interrupt dialogue. The thrust of this method is to achieve uniformity and thus clarity. This instrument is designed according to the principle of standardization, with the aim of ensuring that every patient is presented with identical cues. Any differences among patients are presumed to be real, not a product of procedural errors. The problem is that interpretation is overlooked because the goal is to achieve clarity through methodologic rigor. How these cues are defined locally is not important.

For some time, scholars in philosophy have been trying to reconcile subjectivity and objectivity, including in discussions of ethics. Sometimes these proposals in health care begin to consider, for example, the importance of empathy, compassion, and emotional management/support or respect, and recognize the importance of attitudes and practices supported by the humanities. The problem is that, for the most part, these forays continue to operate in a dualistic framework and thus struggle to include the human element. Universal rules are regularly operative, with the proviso that they be tempered by situational conditions. In these cases, local knowledge may only supplement a clinical application.

Take the work of Beauchamp and Childress, for example. Traditionally, their position has been associated with principlism and the search for universal rules for making clinical judgments. But these authors responded to their critics and are now recognized to be more flexible and pragmatic than originally conceived. Making ethical decisions, they acknowledge, is hardly simple and involves context, conflicting positions, and compromises, that is, balancing a host of opposing positions. Nonetheless, the work of Beauchamp and Childress is hardly narrative-based, and they seem to be merely equivocating about the nature of the information needed to make sound decisions.

A narrative-based ethical practice, on the other hand, is world-centered and does not strive to achieve objectivity. In this sense, dialogue is not merely a conversation or reciprocity that tries to facilitate the transfer of information. On the contrary, as Gadamer describes, dialogue is achieved when the boundaries are crossed that separate worlds, which allows a “unified picture of illness to be achieved” by entering the worlds of a patient or community. Furthermore, these patients are neither manipulated nor misconstrued but grasped in their own terms, without being cajoled by preconceived diagnostic schemes or other clinical instruments.

In clinical practice, world entry begins by both patients and clinicians recognizing how they are interpreting and thus constructing a world. As part of this reflection, they begin to realize that their respective perspectives are limited and that others have legitimate viewpoints that should receive consideration. They can thus cross the boundaries of their respective worlds and enter the worlds of others. Through a dialogical process of give and take, an iterative activity, physicians can verify that world entry occurs and ensure that a correct reading takes place. In this framework, clinicians must go beyond seeking patient contact, detailed
CONCLUSION

A guiding question of narrative-based ethics is “whose reality counts?” With social life consisting of a constellation of narratives, fundamental to earthly ethics is the protection of each story. Ethical judgments and the proper reading of these worlds are fundamentally intertwined. In short, when the impact of narratives is recognized, interventions should extend beyond simply seeking periodic input from patients; the standard consultation or conversation is no longer sufficient. Patients or communities, instead, should be central to determining the narrative that is relevant and how the pertinent storylines should be read.

The training of narrative-based lay health workers in a recent health project on the Island of Granada provides an example of this philosophy in action. This project was devoted to assessing women’s breast health. Although Grenada has only 100,000 residents, the island has a high rate of breast cancer. The point of this project was to train 10 women as lay health care workers who could help screen patients and connect individuals to a medical home.

The aim of the initial stage was to conduct a health survey in the neighborhood that was the focus of the project. After all, breast health does not occur in a vacuum. But the instrument used had to be validated by the community. After consultations with various members, through house-to-house contact, this survey instrument was altered in language and content. Two results of this community validation were important. The first is that better data were collected, and second, better rapport was established with the community.

After this phase, a dialogue was initiated with women in the community about breast health. The point was to discover how these women understood breast health, whether they were comfortable talking about breast abnormalities, and if they felt confident learning to conduct breast self-examinations. The goal was to enter the world of these women through dialogue. The lay health workers, accordingly, received instruction not simply in interviewing—an exchange of information—but how, through reflection and iteration, to make sure they were hearing what the women in the community were actually saying.

As illustrated in this example, practitioners and their patients or communities should approach each other as partners in the search for truth. Accordingly, clinicians and other practitioners should double-check or reflect seriously on what patients express, especially language that seems familiar, for these expressions are easily taken for granted and misunderstood. They should work together to ensure that nothing is ignored or misconstrued. Additionally, a wide range of input should be pursued, beyond the usual case history, to give an adequate portrayal of a patient’s world. After all, what may appear at first to be minor details of a person’s narrative may be truly important.

As part of narrative-based work, and key to world entry, clinicians should realize that all patient or community stories are rational, although the reason that is expressed may, at first, not make sense. A patient’s narrative may appear to be bizarre at first glance—such as excuses for not taking medication or not following through with a treatment regimen—but with a dialogical interrogation, the rationality that is operative can be revealed. Even if a physician believes that the rationality exhibited by a community violates good medical practice, for example, only through dialogue will attitude change come about in a reasonable manner. Through world entry, the rationale can be exposed and appreciated that is crucial to a relevant, and thus nonmanipulative, discussion, assessment, and course of treatment. By adhering to this strategy, practitioners and caregivers may avoid harm, while engaging individuals and communities in a respectful manner.

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