

Primary Health Care and Narrative Medicine

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ABSTRACT

Primary health care has received a lot of attention since the Alma Ata Conference, convened by the World Health Organization in 1978. Key to the strategy to improve health care outlined at the Alma Ata conference is citizen participation in every phase of service delivery. Although the goals of primary health care have not been achieved, the addition of narrative medicine may facilitate these ends. But a new epistemology is necessary, one that is compatible with narrative medicine, so that local knowledge is elevated in importance and incorporated into the planning, implementation, and evaluation of health programs. In this way, relevant, sustainable, and affordable care can be provided. The aim of this article is to discuss how primary health care might be improved through the introduction of narrative medicine into planning primary health care delivery.

INTRODUCTION

Primary health care (PHC) is receiving significant attention nowadays. Most discussions about care, for example, center on the need for early intervention, education, and prevention. Although this approach is driven mostly by economics, other factors are involved.^{1,2} Particularly since the Alma Ata Conference, convened by the World Health Organization and held in Kazakhstan in 1978, PHC is recognized to have political and other significant social dimensions.^{3,4} Indeed, an entirely new philosophy and practice of care are advanced. Nonetheless, although the promise has been great, only a piecemeal strategy has been adopted to implement this outlook.

Noteworthy is the challenge to traditional biomedicine; PHC is by nature more holistic.⁵ The reason for this expansion is quite simple: interventions are not directed at persons or communities divorced from their mediating social conditions.⁶ The focus, therefore, extends beyond biological factors and includes the social and cultural determinants of health. The phrase that has been introduced to characterize this orientation is “person-in-environment.”⁷

PHC interventions are more expansive than those associated with the biomedical model. Many factors that were once thought to be ancillary to formulating an adequate treatment plan are now central. What is thought to constitute evidence and adequate practice has expanded.⁸ Using a standard checklist or symptom scale to gather patient information, for example, is no longer adequate.^{9,10} Furthermore,

persons are understood to engage their environments. In other words, they operate on the basis of conceptual schemes and definitions that are vital to competent planning. Local or community knowledge is crucial to formulating an appropriate and successful intervention.¹¹ In this regard, joining narrative medicine and PHC might bring to fruition the alternative provided by PHC.

PHC is not passive. Practitioners do not wait to act until problems arise and persons decide to pursue treatment.¹² Particularly important is that health practitioners attempt to gain entry to the lives of persons or communities to become attuned to their respective knowledge bases, perspectives on problems, and views of appropriate remedies. At this time, community health workers of various forms—community nurses, lay community health workers, and *curanderos*—are working daily to bring health care closer to persons and communities.¹³ Care is thus offered in a timely and relevant manner.

PRIMARY HEALTH CARE

As can be imagined, this shift to PHC requires that typical health systems be entirely revamped.¹⁴ Often parallel and competing modes of care exist. For example, individual physicians, private clinics, and general hospitals often serve as rival points of entry, with communities left out of the picture. Given this scheme, persons can choose to go to their own physician if they have health insurance, or a public emergency room if they lack this source of payment. Entry into the health system is variegated, and often haphazard, with highly variable costs.

Although definitions are difficult to pin down, PHC extends beyond primary care.¹⁵ Whereas primary care often represents simply an expansion of basic medical practices to a community, PHC includes universally accessible services that are offered in a socially appropriate manner. Furthermore, these preventive, promotive, and curative practices are grounded in the context of substantial community participation. Partners in Health has used this strategy quite successfully through the use of an accompaniment model.¹⁶ As a result, relevant and affordable services are made available.

A significant by-product of this change is that access to the health system is streamlined. Specifically, because of the emphasis placed on local knowledge and customs, the community serves as the single point of entry. Lay community health workers, for example, have become very skilled at identifying problems, applying remedies, and making referrals in low-income countries. Through this sort of “task-sharing,” care is decentralized.¹⁷ The operative principle is that most

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of the problems encountered by persons are dealt with at the level of the community. Additionally, any further treatment is directed through a stepwise series of advances in care.

On the basis of local knowledge, a program of education, prevention, and support can be designed that keeps persons out of emergency rooms and hospitals. And if more sophisticated treatment is needed, for broken bones or other injuries, a rational and progressive regimen is followed. All the while, and particularly noteworthy, persons and communities are learning to monitor and protect their health.¹⁸

This entire process, however, is predicated on the idea of early and community-sensitive interventions.¹⁹ Through education, for example, local health workers can inform their neighbors, identify problems, and make treatment suggestions that seem feasible. As a result of this regular contact, bonds are established that foster insight that is often inaccessible to traditional medical professionals. These community-based interventions have proven to be effective and sustainable.²⁰

Also because of this new point of entry, problems are addressed in their environments. Indeed, holism is almost unavoidable when persons and communities are understood to be far more than organic in nature. In fact, in PHC personal and community problems are enmeshed in a social-cultural environment. Persons, or the so-called hosts, are presumed to interact with their surroundings, although in the medical model this connection is often minimized.²¹ How communities interpret or construct the onset of illness, including their responses to any maladies, is not a part of this truncated holism. In the end, PHC elevates in importance factors that biomedicine acknowledges only reluctantly, if at all.

LIMITS TO BIOMEDICINE

As part of this shift to holism, another facet of biomedicine is challenged. That is, problems are viewed no longer as primarily physical. In a classic article in 1977, Engel²² argued that the only acceptable approach to health is one that is *biopsychosocial*. Most important about this change is that these elements are neither autonomous nor represent separate dimensions of illness. Such descriptions would only upgrade minimally the biomedical model. What occurs when biology is sequestered from psychosocial considerations in these ways is that psychological states or social factors are thought to either aggravate or ameliorate physical ailments.

In this abbreviated holism, the physiology of an illness may be modified slightly by mental conditions, although persons remain psychophysical mechanisms.²³ What Engel and others have in mind, however, is far more reaching. According to this scenario, the biological dimension is enmeshed in social life and, as a result, is mediated fully by this influence. In other words, biological changes cannot be encountered outside of how they are interpreted, classified, and addressed. The biological realm has no identity without a connection to the psycho and social spheres of existence.

Although criticized by Engel, in PHC the dualism, sometimes known as Cartesianism, that justifies sequestering these elements is dismissed.²⁴ Owing to the fact that persons and

communities engage their environments, the impact of this action should not be ignored or downplayed. How persons interpret themselves, others, and their respective situations provides a framework for assessing and remedying physical problems. Some contemporary writers refer to this confluence of action and everyday existence as the “life-world.”²⁵

With regard to PHC, this shift in terminology is very important. When a community is understood as a life-world, the human quotient is elevated in significance. Specifically noteworthy is that the body is penetrated by interpretation, along with other facets of life, and thus illness is a matter of perception and evaluation. The seriousness of an issue, for example, depends on the interpretive scripts that are operative.²⁶

Now an activist strategy is truly needed to identify and prevent problems. Because bodies, persons, and communities are no longer objects, gaining entry to the accompanying information pool is not optional or secondary to the discovery of the physical causes of illness. Borrowing from Pollner,²⁷ the so-called mundane experiences of pain or injury hold the key to creating a successful health program. The stories persons tell about themselves and their communities, in other words, are essential to the proper identification and analysis of a health issue.²⁸

ENTER NARRATIVE MEDICINE

Narrative medicine is usually associated with the work of Rita Charon,^{9,10} but in the past few years the contributions to this area have been expanding. Although not necessarily linked to community practice, the narrative perspective is clearly relevant to initiatives such as PHC. Charon^{9p4} defines narrative medicine as the ability to “recognize, absorb, interpret, critically understand, and be moved by a patient’s story of illness.” Note, this version of narrative is not merely an expanded medical history. Charon and others have something much more profound in mind. In short, the point is to discover the meaning or the existential character of illness.

At the core of this approach to medicine is the literary theory that rose to prominence during the 1990s with the arrival of poststructuralism.^{29p33-51} The emphasis at that time turned to interpretation—the so-called “linguistic turn”—and the impact of language use.³⁰ Particularly significant was the recognition of Wittgenstein’s view of language and the subversion of the standard indexical theory. Specifically, Wittgenstein³¹ argued that language functions not like a pointer but like a game. According to the indexical thesis, language indicates, highlights, or differentiates the content of perception. All the time, however, these elements are presumed to be objective. Physical symptoms, for example, are considered to be real markers, although they can be obscured by personal or collective perspectives.

Stories of Lives are Informative

Wittgenstein, on the other hand, proposed that how the language game is played shapes perception. The content of perception, accordingly, is not objective but given meaning and arranged by language use. Because language has this

power, those who practice narrative medicine contend that the stories persons weave about their lives are truly informative.³² A lot of vital information is missed, they maintain, if these narratives are obscured by biology. In other words, interpretations do not merely conceal physical reality but shape how these factors are known; these interpretations, therefore, embody the reality of persons and should not be dismissed as impediments to acquiring accurate health data.³³

Within the context of Wittgenstein's philosophy, biology constitutes simply another descriptive.³⁴ Proponents of biomedicine, however, elevate this narrative to such a degree that all others are marginalized. The result is a style of reductionism, couched in science, which many practitioners do not recognize. That is, biology is treated as the naturally dominant, and thus most accurate, source of information. Physiologic symptoms and markers, therefore, are the obvious indices of disease.

Proponents of narrative medicine claim that this focus is too narrow. Their point is that many other narratives may be operative, and if these stories are not consulted medical interventions will be poorly designed. After all, how persons interpret, evaluate, and react to symptoms plays a crucial role in whether a problem is understood to exist.³⁵ A problem, in short, does not reside in a realm free of narratives.

The Clash of the Physician and Patient Stories

Often the clinical or technical story desired by a physician and the cultural or economic narrative told by a patient clash. A physician may want to know how long certain symptoms have been present and whether treatment had been sought earlier. A patient, on the other hand, might want to talk about his or her past experiences with physicians, what any symptoms mean, and why treatment was not an earlier option.³⁶ What should be noted is that the patient's narrative offers vital insight into the path of treatment and how services might be offered effectively.

In the past, these stories were viewed to be a distraction. At that time, biology was the sole valid explanation of any problem, and other narratives were treated as simply unreliable for making decisions.³⁷ These personal or collective experiences did not accurately depict reality. In conventional medical practice, the biases present in these tales had to be overcome before sound interventions could be developed and implemented.

Biology as Narrative

In narrative medicine this trend is altered. Biology is not excluded but becomes one of the many narratives that should inform a diagnosis or treatment plan. In terms of Wittgenstein's proposal on language use, nothing, not even biology, is immune to interpretation.³⁸ All narratives, therefore, must vie for relevance, since none is more valid inherently than any other. In point of fact, no objective conditions are available to make this determination. In narrative medicine, nonetheless, the application of these stories is not haphazard. The values, beliefs, and commitments of persons or communities

are central to identifying the narratives that are pertinent to examining properly a condition.

In PHC, these stories are not add-ons.³⁹ They do not merely supplement more profound biological data but are central to correctly deciphering symptoms and why persons react in one way or another to these signs.⁴⁰ So-called physiologic markers, the gold standard for making predictions, are now contingent on the basis of the narrative that emerges as dominant. This process of emergence encompasses many features of a person's individual existence or life in a community and is not easy to predict. Nonetheless, health behavior cannot be extricated from this activity.

NARRATIVE AND COMMUNITY

Because of the importance of narratives in community work, PHC requires a situated response—the relevant narrative provides the standpoint that should be used to judge an intervention. But at this juncture a particular caveat is important that is not stressed in narrative medicine. Specifically, narratives are never written or judged alone. Narratives, in other words, are a collective endeavor.

Narratives are always written with others, such as neighbors, friends, acquaintances, and rivals.⁴¹ No one exists in isolation; no one is an island. As a result, only in rare instances will a community offer a single narrative of any phenomenon, particularly health. Hardly any community is this homogenous. In most cases, similar to the stories told by individuals, a community will provide many, often conflicting narratives.

How a community views illness, and responds to the onset of a problem, will be varied and shifting, and represent several logics. This diversity, however, does not mean that the presence of various storytellers undermines any prospect of a coherent analysis. This diversity does not mean that no rationale is available for analyzing a community's problems. But any final explanation is going to be variable and multifaceted. Those who work in PHC must be attuned to where these narratives merge and diverge, and how these shifts occur.

Narrative medicine, accordingly, consists basically of listening attentively to patients and, possibly, exhibiting some empathy. But these methods may not go far enough to capture the narratives present in a community. Making sure that a symptom checklist is understandable may not be sufficient in this regard. The following examples represent attempts to extend the principles of narrative medicine.

Two Examples of Engaging Story in Community

The first two examples are drawn from a recent health project on the island country of Grenada. In this project, community members were trained to become lay community health workers who would eventually administer a general health status survey. These persons were allowed to review and to correct this instrument to ensure that the proper questions were asked and the appropriate language used. In this way, the health narrative of communities could be correctly engaged.

But in such a project the parameters of a community must be understood, so that interventions can be targeted properly.

Therefore, a process of community mapping was undertaken. The basic idea is to walk around a community and identify households, resources, streets, and, if possible, the boundaries of this locale. Often, as part of this activity, persons come out of their houses, answer the questions posed by the mappers, and debate issues, such as where a community begins and ends. This input is crucial to creating a community map that reflects the everyday experiences of persons and the local reality.

The final example relates to a health project that is ramping up in a Hispanic community in Los Angeles. In this project, community members will be trained to be lay community health workers. Especially noteworthy, a community health committee will be organized to guide every facet of this project. This group will be responsible for creating all assessment instruments and interview guides, along with interpreting any findings and formulating the policies derived from this data.

More Than Listening

The aim of these examples is to demonstrate that gaining access to the narratives of persons or communities may require more than simply listening. For example, an interview grounded in narrative theory is unique in several ways. In a traditional methodology, an interview schedule is preconstructed, standardized, and designed to be clear. One that is based in narrative medicine, on the other hand, is co-constructed with patients, situationally relevant, and intended to gain insight into persons' lives. The purpose of this co-construction is to increase the prospects for real listening and the creation of situationally appropriate interventions.⁴²

In narrative medicine, active participation in the care process is required to provide relevant treatment. After all, if the proper questions are not asked, and irrelevant language is used, patients may not be addressed in a manner that elicits accurate information. Clinicians, accordingly, must be willing to examine critically their interview guides and similar instruments, and offer the opportunity for correctives to be provided by their patients. An interview in narrative medicine is dialogical, with all participants actively involved, whereas a standard checklist or other typical strategy is constructed and guided by professionals and thus not conducive to dialogue.

Those who are interested in this strategy must recognize that persons may create very different illness narratives, although they share a common social space. Likewise, individuals may construct conflicting narratives of themselves. Why certain narratives have validity, while others do not, is clearly important to organizing a proper intervention. Additionally, the procedure whereby stories gain traction, and become dominant, is essential to understanding how particular perspectives achieve longevity and others disappear. As a result of appreciating these dynamics, a holistic picture of persons and their community can be provided.

But a community is not simply a composite of discrete narratives. Although all stories are not necessarily dispersed evenly throughout a community, they are associated in many ways. Why and how different narratives become acceptable provides a point of access for understanding an entire

community's perception of and reaction to illness. The ability to map these differences, moreover, provides the basis for a unified and informed picture. As noted by Niklas Luhmann,⁴³ the recognition of differences supplies the framework required for a unified gestalt.

CONCLUSION

Certainly the preservation of health is truly an existential issue, and PHC is no exception.⁴⁴ At times health status enhances options, whereas at other times, it limits what persons can expect and accomplish. Specifically, a core existential issue is the ability of persons to choose freely and to act on the basis of these decisions. Obviously health plays a key role in this process.

How persons define themselves, and plot their futures, is a story that extends beyond biology. Interventions that are designed to perpetuate or to restore health, accordingly, require a holistic and culturally sensitive focus. After all, most persons do not conceive normality in solely physical terms. Their aim, instead, is to achieve a healthy existence and resume their usual tasks. Their obligations, for example, are social and not necessarily focused on biology.

In PHC, owing to the emphasis placed on persons and their environments, narratives assume a collective character. Whether persons choose to seek treatment, for example, is often influenced by a range of stories, some of which are dominant only at particular times. The source of this influence may be not the biological narrative but those related to gender, race, or poverty. The physician should allow the proper narrative to emerge and begin to shape clinical and other discussions about health.

What should be clear is that PHC is not simply an extension or modification of biomedicine. A new model is proposed that treats the various dimensions of illness as existential and embedded in narratives, while expanding the traditional role of physicians. The biological narrative, accordingly, may not necessarily be dominant among particular persons or communities. But such a decision does not automatically signal irrationality but simply the acceptance of a different order of values and commitments. Those who engage in PHC must make sure that these persons' stories are correctly identified and told, rather than dismissed because a particular narrative might deviate from medical convention. ❖

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Story

The doctor may also learn more about the illness from the way the patient tells the story than from the story itself.

— James B Herrick, 1861-1954, American physician