The transformations of disease in expert and lay medical cultures

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ABSTRACT

Every culture has rules for translating signs into symptoms, for linking symptomatologies to etiologies and interventions, and for using the evidence provided by interventions to confirm translations and legitimize outcomes. The path a person follows from translation to socially significant outcome constitutes his sickness (Allan Young 1982. p. 270).

Key words: Ayurveda, biomedicine, theoretical medicine

INTRODUCTION

Professional health care providers, folk healers, and common folk all hold ideas about diseases, their causes, and their remedies. Medical cultures are shared by professionally and regionally bounded groups of people who apply similar disease categories (nosology), disease explanations (etiology) and treatments (therapy). Indeed, western biomedical physicians, college educated Ayurvedic physicians and locally bounded communities share a medical culture or a medical ethos (outlook). These expert and lay perspectives on health, disease, and the body are embedded in a wider worldview or cosmovision. Therefore, the many medical theories current in today's world may be seen as different readings of reality. In other words, all medical styles of knowing have their own unique way of understanding and treating the signs of disease. Both expert and lay medical cultures represent one out of many possible interpretations of disease defined as somatic and behavioral dysfunctions. They differ, however, in the signs they consider to be paramount and they transform the selected signs of disease into symptoms that are meaningful within their medical paradigm. Indeed, all medical cultures – global or local, lay or expert – have their own disease categories (ontology), and their own methods for constructing, validating, and transmitting medical knowledge (epistemology). Medical constructs do not present us with mirror-like representations of the human body and its ailments. Medical theories are one thing and lived diseases another. We must therefore not confuse the map (medical theory) with the terrain (disease). This paper takes the view that medical theories and practices are social constructs that are voiced, applied, and circulated by groups of people sharing the same medical culture. Medicine is culture dependent, not culture independent. We look upon medical systems as social systems when we take the broader cultural and political context in which medical theories are constructed and medicine is practiced into account. Such a perspective makes it possible to challenge the superiority claim of western biomedicine.

To come to grips with the many medical theories and practices in today's world the common English words "disease," "illness," and "sickness" – used indiscrimately in daily life – are used as analytical categories. The term "disease" is used to refer to somatic and behavioral dysfunctions as signs of worrisome physical and psychological states that precedes their framing by one of

> More is at stake in the interpretation of illness than a set of medical practices (Charles Leslie 1992. p. 205).

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the many medical logics. Though medical cultures have their own perspective on disease conditions like fever, pain, and anxiety, these are concrete phenomena. Central to the social-cultural perspective on disease is "sickness." Every medical culture – lay or expert, global or local – converts signs of disease into socially significant and publicly accepted outcomes, designated here by the term "sickness."[1] Disease also has a psychological dimension, which is linked to individual perceptions and coping strategies. Experience of a disease and how it is understood on the individual level, is designated by the term "illness."

My discussion begins with Ayurveda, India's most practiced medical tradition.[2] Ayurveda is used here as a case to argue that in order to prevent western biomedicine's "fatal embrace" we must acknowledge the uniqueness of and necessity for traditional medicine.[3] Like all medical systems Ayurveda has its own way of "taming" somatic and behavioral dysfunctions. Next, I shift my attention from medicine as expert knowledge to lay medical knowledge and discuss how people deal with disease when living with it becomes a reality to them.

COLONIZATION OF TRADITIONAL MEDICINE: THE CASE OF AYURVEDA

The inroads of modern science in Indian society and the world at large explain the biomedicalization of Ayurveda in the 20th Century. The dominance of biomedicine and its positivistic and materialistic epistemology led to the biomedical framing of the medical substances, notions and practices of traditional medicine. Stridently positivistic reading of the classical medical texts of scholarly Asian medicine such as Ayurveda, Traditional Chinese Medicine and Tibetan Medicine often edited out everything that does not conform to the notions of modern sciences such as biology, pharmacology and biochemistry. Indeed, traditional medical categories such as the srota in Ayurveda, the seven phases in Chinese medicine and Asian concepts of vitality such as ojh, chi and prana and shen have been tortured and violated as the case of modern Ayurveda amply illustrates.[4] To avert this we must acknowledge the differences in approach of biomedicine and traditional forms of medicine and work toward:

(…) paradigm shift in design of clinical trials because traditional health systems adopt a customized and multipronged strategy in treatment … [and focus on] improving systemic functioning … achieving homeostasis, rather than eliminate a specific agent(s)… aiming at both mental and physical well-being.[5]

When we deny the difference between the analytical style of knowing of biomedicine, and the synthetic way of looking at the body, health and disease of traditional medicine, we lose alternative medical epistemes and treatment modalities that offer much needed alternatives. If we want to keep these medical traditions for the sake of ailing patients and inventive scientists, we should develop and employ research protocols sensitive to the logics and therapeutics of Asian medical traditions. Good research on Ayurveda must take into account its perspective on health as a multisided positive state, and its treatment objectives such as dissolving blockages that hinder the flow of nutrients, the building of good quality tissues and the expulsion of waste products, and the balancing of the body's systemic functions to improve its innate healing capacity. The structural and cultural dominance of biomedicine and its style of knowing has led to undue -- in the sense of not proven -- claims of its epistemologically superiority and its assumed greater efficacy and efficiency. It is by definition impossible to judge logics against each other, because each of them represents a different perspective on the phenomenological world of health, disease, and treatment.

This does not mean that positivistic research is not necessary for good medical practice in scholarly and other forms of traditional medicine. Modern pharmacological laboratory research is needed, for example, to guarantee the quality of industrially produced traditional medical products available in the market. The presence of examples of substandard products in the market is a threat to the integrity of traditional medicine. But also at the village level where folk medicine based on local medical lore is practiced we have to be cautious. Here laboratory research is not the first option, because of the costs involved. Strengthening local networks that enhance accountability of health care providers, as well as participatory research strategies to sift useful medical practices and materials from those that are harmful, are urgently needed. The rapid assessment method for local health traditions (RA-LHT) developed and implemented by the Foundation for the Revitalization of Local Health Traditions (FRLHT) over the last decade is one the rare attempts in this field. The 21st century sees an increased appreciation of, and investment in, traditional medicine; both in its scholarly, folk, and CAM variants.[6] In the case of Ayurveda the recent appearance of peer reviewed research journals such as the eJournal of Complementary and Alternative Medicine, AYU, Asian Medicine: Tradition and Modernity, the Journal of Ayurveda and Integrative Medicine and the International Journal of Ayurvedic Research, testifies hereof.

Apart from professional and institutionalized medical systems such as biomedicine, Ayurveda, traditional Chinese medicine and German herbal medicine, we also have the medical cultures of lay people. These locally bounded

medical cultures hold medical ideas, practices and remedies of their own. Like expert medical systems, lay medical cultures frame disease when they name, explain and act upon somatic, psychological, and social distress. They provide us with models of, as well as models for, the body, health, and disease. In the next section, we will look at medicine from the perspective of the health seeker and his or her therapy management group, e.g. the health seeker's relatives, neighbors, and culturally important others.

TRANSFORMATIONS OF DISEASE BY PATIENTS

For individual patients medical treatments are only effective when they are locally available, economically feasible, and make sense within their life world. Collective representations of medical systems and diseases determine if and how patients make use of available treatments. During the health-seeking process, disease is given socially recognized meaning as sickness, which is the process for socializing disease. Diseases are identified, named and explained, and treatments are selected, applied and evaluated, when patients and their family members are looking for a cure. In this process diseases are turned into socially significant and publicly accepted outcomes. Personal experiences with diseases and treatments are explained and converted into disease strategies through symbolic reasoning which is the leaven of the human imagination.[7] Symbolic reasoning is human imagination at work. Here, metaphors and metonyms link empiric observations of medical treatments and their outcomes to strategies for dealing with disease. Patients looking for a cure employ a combination of empiric and symbolic logic. In this they do not differ from health care providers, because,

(...) despite the importance of science for modern medical research, judgments of efficacy by allopathic [biomedical] health professionals for the most part resemble those of indigenous physicians and laymen. They are empirical, based on pragmatic experiences with different practices, and symbolic constructions that satisfy because they make sense, or seem appropriate.[8]

Patients and health care providers alike give meaning to their experiences by contrasting and connecting them with each other, and because medical beliefs and practices have permeable borders they regularly break down the partitions between medical systems. In daily practice medical systems that policy makers and scientists want to keep separate for the sake of their policies and discussions, often overlap.

To get a better grip on the health seeking behavior of lay people we will first look at a case that illustrates the translation in the clinical encounter between a local healer and his clients of the signs of disease. Then I discuss the phenomenon of cultural reinterpretation and argue the permeability of borders between medical systems. Subsequently, we will see that the term "medical pluralism" must be used with caution. Finally, I will reason that tapping into local idioms of distress and the usage of traditional medical technologies and substances can be an asset in the treatment of disease as a lived experience.

THE WORK OF CULTURE

The work of culture gives meaning to disease and turns somatic and behavioral dysfunctions into sickness. An example hereof comes from research done in the areca nut belt of the state of Karnataka in South India by the medical anthropologist Mark Nichter in the 1970s.[9] Nichter describes and analyses the clinical encounter between a young woman who works as a roller of beedis (local cigarettes), accompanying family members and a scholarly Ayurvedic physician. The complaints presented to the medical practitioner by the patient and her family are: whitish discharge, back pain, insomnia, loss of appetite, lack of work interest, and general malaise.[10] Though the patient had visited two other medical practitioners before who had prescribed red pills (unidentified), B12 vitamin injections, a tonic and a talisman, no improvement was made. The encounter with the third healer, who practices a form of Ayurvedic medicine based on his family tradition, is more successful. During an elaborate clinical encounter the practitioner links the signs of disease to the patient's wish to marry and her family's resistance because they partly depend upon the young woman's earnings. Though three medicines were prescribed -- to enhance weight, to build tissues (dhatu), to purify blood and to enhance sleep -- communication between physician, patient and her family members was equally important. With the help of Ayurvedic insights such as prakriti (individual somato-psychic constitution) and the classifications of emotions, life-phases, foods and seasons, the hidden wishes and longings of the patient are made explicit and acted upon. In the clinical encounter, painful somatic and psychological states were transformed into publicly accepted meanings and practices. It was decided that the woman could keep most of her earnings and that the family would look for a suitable bride groom.

This example illustrates that the work of culture shapes somatic and psychological distress and by doing so provides patients with a treatment that acknowledges the realities of their day to day life.[11] Formative processes of a social-cultural nature turn disease into a socially accepted form.[12] Culturally bounded idioms of distress are

instrumental in the conversion of disease into sickness and cure. The disease trajectories of patients and their outcomes are contingent upon culturally bounded ways of naming, understanding and treating disease. For example, in the Sri Lankan context, the Buddhist notion of life as suffering can be seen as a cultural representation of depression which gives handles for the treatment of this ailment. Sri Lankan Buddhist culture transforms "painful motives and affects such as those occurring in depression (...) into publicly accepted sets of meaning and symbols."[13]

Not only collective representations of diseases but also the way patients look upon medical systems informs treatment choice and illness trajectories. A case in point is the observation that:

(...) patients prefer traditional medicine on account of their distrust for biomedicine. This distrust reportedly has arisen both from the memory of poor experiences with government clinics and from the association that they have drawn between biomedicine and the very processes of modernization that they blame for their ailment.[14]

The quote explains why people living with HIV and AIDs (PLHA) in South India prefer Siddha medical treatment. Negative experiences in biomedical government clinics due to unpleasant treatment by the staff and lack of medicines combined with the local representation of HIV/AIDs as a disease caused by modernization and the decline of local morals and practices, explains why people think that they are better off with traditional medicine.[15] Here, western biomedical drugs are not seen as the right antidote against HIV/AIDs and patients prefer a remedy that is "antagonistic" to the imagined west, e.g. medical treatment based upon, and consisting of, Indian medical notions, practices, and substances.

CULTURAL REINTERPRETATION

It is important to keep in mind that collective representations of diseases and treatments are unequally distributed among members of a bounded cultural group. Images and perceptions change with the times, are employed in strategic ways, and are both embraced and critiqued. Culture does not work in a mechanic and deterministic way, but provides people with more than one way in which somatic and behavioral dysfunctions can be converted into socially recognized sicknesses. Social science research over the last four decades shows that patients are flexible when it comes to explaining and treating disease. Explanatory models are accommodating, do not exclude each other and are arranged into hierarchies. Disease explanations are negotiated in medical settings and move along with the medical systems that are consulted and the treatments that are applied. Multiple therapeutic uses and not disease-specific patterns of resort seem to be the norm.[16] Patients do not necessarily consider the disease explanations and treatments coming from different medical systems as contradictory. The fact that patients and health care providers hold different medical logics does not necessarily undermine treatment.[17] The South Asian notion of disease as imbalance reconciles seemingly opposing medical paradigms as shown by the example of a young Sri Lankan woman with severe mental problems who was sequentially taken to an Ayurvedic practitioner, an exorcist and a biomedical psychiatrist. An eclectic pattern of resort did not lead to confusion among the girl and her therapy management group, because in the health seeking process, treatments

(...) are linked by an underlying continuity of process in which the personal antecedents of the illness are reinterpreted in terms of public representations of affliction and in which all treatments phrase illness most basically in terms of excess and imbalance.[18]

The various explanations for the woman's suffering by the consulted health care providers were absorbed in a cultural metaparadigm in which notions of overload and shortage explain disease as well as other misfortunes such as a failed harvest or political unrest.

MEDICAL PLURALISM AND THE MEDICAL MARKET PLACE

In India as elsewhere, medical pluralism -- defined as a country's diverse range of healing systems and the many combinations in which patients seek them and healers practice them -- is a reality.[19] An array of medical systems through which patients, care givers and the public engage and formulate reality in a medical way, exists in the socially stratified and culturally diverse societies of today. Though biomedicine is structural powerful in the sense that policy makers at the national and international level are linked to biomedicine in a professional and cultural sense, heterodox forms of medicine thrive everywhere. They cannot be wished away by those belonging to the medical establishment, or by people who doubt the quality of some of the traditional medical treatments on offer. Quackery is not confined to traditional medicine but is also a reality in biomedical practice.[20]

We must, however, use the term "medical pluralism" with caution, because the term suggests that there exists a medical market place where there is fair competition between medical systems and freedom of choice for patients. This is not in agreement with reality. Competition is not fair when biomedicine is treated as state medicine.

Moreover, are there many constraints that prevent patients from freely choosing the treatment they prefer. Structural factors like affordability, availability and social inequality, as well as cultural factors such as acceptability, constrain the options available to patients and the way they make use of them. The notion of a medical market place denies that medicine:

"(...) is inevitably associated with politics, and in practice, it is often structured from above, albeit frequently disguised as increased choice or fulfilling the rights of individuals".[21]

Recent research done in Delhi, for example, shows that in case of cancer, male bread winners are given biomedical treatment, while other family members are taken to traditional practitioners who are usually cheaper.[22] Finances, health insurance systems, government regulations, and social inequalities, all shape the relations between medical systems.

LIVING CULTURE, LIVING DISEASE

It is well known that stigmatization of disease hinders treatment and blocks recovery. Cultural notions and practices can aggravate disease, but at times they also offer the images and therapies to mitigate them. An example comes from a recent ethnography, in which the author analyses the transformation of an Indian religious sect (Kin Ram Aghori) into health care providers for those suffering from skin diseases such as leukoderma (vitiligo) and leprosy.[23] According to the medical anthropologist Ron Barrett who stayed for almost two years with this healing sect, the social and psychological aspects of these infamous diseases are the main focus of their treatments. Though these Aghoris prescribe and distribute Ayurvedic medicines manufactured by themselves, intelligent usage of Indian key metaphors are equally important. These Aghori healers tap into the Indian metaphor of disease and other misfortunes as impurities, which can be taken away or neutralized by, for example, a visit to a temple, bathing in a holy river, or the blessings of a sacral person. The Kin Ram Aghoris are said to have achieved a spiritual state that enables them to neutralize the "poisons," which are the cause of infamous skin diseases. The holy river Ganges provides the cultural analogy. Like Hindu cremation rites, Mother Ganges is a potent transformer of "impurities" such as sins and infamous diseases. The healing ceremonies performed by the Aghoris are therefore powerful antidotes against the biosocial illness of discrimination from which leukoderma and leprosy patients suffer. Interviews Barrett had with both sufferers and the general public such as shop keepers, market vendors, and students, showed that many linked conditions such as leukoderma and leprosy to an unethical life style, lack of hygiene, and the poverty of beggars. In the Aghori clinics and hospitals in addition to somatic therapy the sickness and illness components of these afflictions are treated. This is crucial because social stigma heavily determines the epidemiologies and trajectories of these skin diseases. The same is true for other infamous diseases such as tuberculosis and HIV/AIDs. Often patients internalize these social prejudices, which makes suffering worse and obstructs treatment. Aghor philosophy as medicine supports and potentiates the somatic effects of the Ayurvedic formulas they distribute to their patients. These substances transfer the dua (blessings) of the Aghori healers. According to this pan-Indian notion the purity of the Aghoris who distribute the medicine is transferred to the patient through these medicines. The patient--healer relation becomes a medicine, and the drug its vehicle. This example illustrates that some diseases are only effectively treated if there is a focus on sickness and consequently illness. This is true for chronic diseases as well. In such cases, somatic treatment can only be successful when there is a shift in focus from cure to disease management. Addressing the sickness and illness aspects of disease is often as important as taking care of the somatic dimension. Body, mind and spirit come together in patients living their disease in both a visceral and cognitive way. A good example of such a comprehensive treatment regimen is the integrative approach for managing filarial lymphedema (Ayurveda: shleepada). Through a combination of Ayurvedic, yoga, and western biomedical perspectives, regimens and medications, the social, emotional, and somatic dimensions of this highly disfiguring skin disease are taken into account.[24]

CONCLUSION

Diseases defined as somatic and behavioral dysfunctions are concrete phenomena, but are understood and treated in different ways. This article started with a brief discussion of Ayurveda with the objective of showing Ayurveda's unique medical perspective, and the danger of biomedically framing its medicines, treatments and notions. Subsequently the focus was shifted to health seekers and we saw that local medical knowledge and practices matter. If we want to improve people's health, we should take local representations of diseases and treatments into account. Traditional medicine is needed because of its cultural acceptability, and because biomedical public health care is often not more than ersatz medicine. Thirty years ago the Indian medical sociologist Aneeta Minocha asked: "What is the ability of the traditional systems of medicine to meet people's felt needs?"[25] Though improvements have been made in the assessment of the state of traditional medicine, and progress has been made in the testing and development of traditional medicine, we still have no clear

answer to this question. One of the reasons is that the logic of biomedicine is shared by policymakers and most of the researchers who advise them. This brackets out the medical logics of traditional forms of medicine and the social-cultural logics of health seekers who do not share the views and sensitivities of biomedical oriented policy makers and researchers. The increasing popularity of traditional medicines as Complementary and Alternative Medicine (CAM) in the West and among the western educated middle class in the South, hesitantly leads to more material and cultural support for traditional medicine as a means to improving the health and autonomy of the poorer sections of society. The popularity of CAM also obviates the suggestion that traditional medicine is pushed upon poor people by those who only want western biomedicine for themselves.

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2. Ayurveda in its professionalized form is the largest and the most prestigious among the many forms of traditional Indian medicine. There are approximately 700,000 practitioners with a government sanctioned degree and a folk sector that consists of an estimated 1,400,000 midwifes, general herbalists, and specialists in the treatment of ailments such as snake bites, orthopaedic problems, diseases of the eye and skin, respiratory problems, diabetes, jaundice, anaemia, reproductive ailments, as well as common diseases such as cough, fever and indigestion.
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