

# The Cultural Meanings and Social Uses of Illness

## A Role for Medical Anthropology and Clinically Oriented Social Science in the Development of Primary Care Theory and Research

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Basic research that is conceptually and methodologically innovative and that fosters long-term research programs should play a role in the academic development of primary care, alongside more practical applied studies of specific clinical problems. A creative tension between the two has been a distinctive attribute of academic medicine and should be fostered in family medicine and other primary care disciplines. The biopsychosocial model offers a paradigm for the incorporation of clinically oriented social science research as one basic science approach in which primary care researchers can receive advanced training and pursue an academic career. The author briefly illustrates such a career with reference to studies (his own included) on the social uses and psychocultural meanings of illness. Somatization, a major problem in primary care, is illuminated by such a clinically applied social science research framework. Developing the scientific basis of an academic discipline involves intellectual education in systematic scholarship to create and critique concepts as much as it requires training in the application of rigorous research design and powerful statistical techniques.

Two levels of academic endeavor should develop in primary care if family medicine and the other primary care disciplines are to become viable academic enterprises: (1) practical applied

studies of discrete, salient health care problems based on specific methods and instruments taken from epidemiology, health services research, biomedicine, and psychiatry that are drawn upon to study highly focused, operationalized research questions; and (2) concepts, theoretical models, and research approaches that can contribute to a unique scholarly discourse on primary care and that can provide the intellectual foundation for self-contained research programs which together create a science of clinical practice.

On level 1 there may not be, nor need there be,

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understanding of the conceptual basis of the research methods imported into primary care, and indeed nonclinician researchers trained in applied or even basic science may be brought in to apply them. But on level 2, researchers struggle with the translation of concepts from other fields into new ways of conceptualizing and analyzing health care problems. They create new methods or remake old ones. They, moreover, ask questions and search for answers at a fundamental level, rethinking core clinical concerns. Level 1 researchers often do not possess advanced research training, or if they do, it usually is not in a basic science. Rarely do they see themselves as contributing to scientific inquiry. They are clinicians who are trying to answer particular clinical questions. For them the best may be the enemy of the good. They want to be able to apply some highly specific research techniques and statistical skills for highly practical purposes. These technologists want their scientific skills to be "good enough" for performing particular research tasks. They are not questioning theory or building long-term research programs whose individual projects are intended to set out and test a line of reasoning. Indeed, it is frequently crucial to the success of such applied studies that their completion is feasible in a relatively restricted time frame. This means that they usually cannot explore a question in great depth.

In contrast, level 2 scholars see themselves very much as scientists who are about the lifetime labor of building a separate field of scientific inquiry. They have been systematically trained to be conceptually sophisticated, to enter, under supervision, a major intellectual tradition, review its sources and the current status of its academic discourse, and engage in critical ongoing dialogue on its core themes and findings. Masters of the ideas behind their techniques, these researchers take theoretical questions extremely seriously and aim to build methods and collect data to systematically advance rigorous and critical testing of ideas. They provide their academic disciplines with intellectual power and scientific status.

In biomedicine it is the creative tension between each of these levels, sometimes even in the same researcher, and the distinctive but related interests they support which sustain that remarkably productive dialectic between applied and basic knowledge, clinical and intellectual endeavor, trade and science that strikes one as the

essence of what has come to be recognized as the best in academic clinical medicine. This systematic tension between theory and practice is what keeps academic medicine vitally oriented to practical problems while at the same time avoiding becoming either (1) unscientific or pseudoscientific, or (2) overly scientific and clinically irrelevant. That there is often an imbalance in some disciplines toward the latter and in others toward the former does not invalidate this goal; it only indicates how important it is to maintain this difficult balance at the heart of clinical science. Further, this is the appropriate model for how the primary care disciplines need to develop if they too are to achieve academic success.

### Current Status of Research

When applied to the primary care disciplines, what does this admittedly ideal-type model reveal?

First, on the applied level, family medicine and the other primary care disciplines are already off to a reasonable start. Primary care practitioners have drawn on the relevant methodologies of biomedicine, epidemiology, health services research, and clinical psychiatry and psychology to conduct individual projects. Researchers from these other disciplines are acting as collaborators. The data base is greatly expanding. A critical mass of researchers has been created that is actively debating future academic directions. These are no small achievements. This practical level of research, even in the presence of severe budgetary constraints, will continue to grow and mature; its principal contribution will be the data it generates about important clinical problems and the academic infrastructure it builds in schools of medicine, both of which will help establish the primary care disciplines as legitimate academic enterprises.

On the second level hardly anything is seen yet. Where are the concepts being built and pulled together into original theory, where are the new methodologies being created to test hypotheses, where are there systematic attempts to train researchers to translate relevant work from other

disciplines, not *this* particular technique or *that* particular experimental design, but key concepts that can help build a major research program? (One of the few signs of this happening is the early, but important, effort of Medalie's family medicine group at Case Western Reserve to form a research program containing several and varied studies centered on the understanding of the family's contribution to social support and its influence on health maintenance and illness outcome.) In the absence of substantial endeavor on level 2, there is a serious imbalance in the creative dialectic between applied and fundamental science in primary care, and this raises the distinct danger of allowing practical research to stagnate and slowly slide into technology divorced from intellectual concern, which eventually must mean poor science or no science of primary care at all, and no clinical scholars in the real sense of that evocative term. Lacking level 2 contributions, primary care may become merely a testing ground for other fields' scientific developments without a core academic program of its own, somewhat like an underdeveloped country that has lost control of its own future to outside colonial interests.

### Needed Directions for Research

So much for the problem. How can it be remedied? The goal is to develop level 2 research in primary care while continuing to strengthen level 1 studies. To do so, it is necessary to train in depth a small number of highly skilled primary care researchers who possess a deep commitment to developing its academic base, each in a relevant scientific discipline that they can master in two to three years of advanced study, whose approach they not only can practically apply—as is done now with faculty training in the Robert Wood Johnson Foundation program—but which they can systematically translate into original primary care theory and methods. Here the desired terminal competency at the end of training is an ability not just to design and conduct individual studies but, more importantly, to develop a long-term research

program. Clinical scholars should be trained who become primary care epidemiologists, others who become primary care health services researchers, and still others who link primary care to specific medical social sciences (anthropology, sociology, social psychology). There should also be primary care physicians trained in relevant biological research approaches. This cohort of young academics would conduct work on both level 1 and level 2, but principally the latter and, it is to be hoped, would receive long-term support from their institutions and academic disciplines to build careers as scholars. Around them would coalesce research groups engaged in the elaboration of well-defined research projects.

One particular area of level 2 research that family medicine and other primary care disciplines can and should actively cultivate, is medical anthropology and other clinical social sciences. The primary care disciplines could become the major venue for the introduction of social science into medicine and for the application of the biopsychosocial paradigm to health care. Social science provides the language and conceptual apparatus to study the psychosocial aspects of illness and care. A science of clinical care requires social science joined to biomedicine and psychiatry as its intellectual basis. But such clinically relevant social science cannot be developed solely by social scientists. Clinician-social scientists and social scientists with clinical teaching and research experience are needed to carry out the difficult but crucial task of translation and integration.

The biopsychosocial paradigm,<sup>1,2</sup> which has been accepted by some primary care practitioners as a model for clinical practice, deserves to be promoted as a powerful paradigm for research that sets the primary care field off from the traditional disciplines of biomedicine, links primary care with other disciplines (notably the behavioral and social sciences), and provides it with an autonomous theoretical and methodological orientation to its subject matter; indeed, it casts that subject matter in a new form which connects it to some of the most interesting current interdisciplinary developments in the academic world (eg, psychoendocrinological and other psychophysiological studies of stress; studies of the interrelationship of stress, coping, and social supports in illness onset; sociolinguistic research on the structure of health professional-client discourse and its influence on

the assessment of therapeutic outcome; medical ethnographic studies of lay help seeking and self-care and their effects, as well as of physicians' work, and the negative impact on them of work-related stress; and much else besides). Since scientific research is increasingly becoming interdisciplinary, the biopsychosocial model is at the very cutting edge of new developments in science. Furthermore, it is a research guide to the study of how key large-scale social problems in health and health care affect the individual patient and clinician at the microclinical level.

The biopsychosocial model as a paradigm for interdisciplinary science *integrates* psychological and social with biological variables and brings the social sciences into medicine in the same way that tertiary care internal medicine specialties build a bridge between medicine and the biological sciences. It is, in addition, a conceptual approach more adequate for a science of clinical care, since it seeks to unite clinical sciences' biomedical and social science bases. Whereas biomedicine has little to contribute to the study of physician-patient communication, the analysis of clinical reasoning, the study of help seeking, and the myriad of psychosocial issues that make illness behavior a crucial problem for clinicians, the biopsychosocial approach is a powerful way of bringing to bear knowledge and research strategies from social science to help examine these and many other relevant issues.<sup>1,3,4</sup> But by insisting on relating social science to biological issues and clinical work, the biopsychosocial model overcomes some of the notable weaknesses of social science studies of medicine that are divorced from clinical perspective and thereby often become irrelevant to primary care. Finally, now that psychiatry seems caught up with the revolution in the neurosciences, at least for the next decade, the primary care disciplines have the somewhat surprising opportunity of becoming the major academic venue for the biopsychosocial paradigm and therefore for social science in medicine. (Of course consultation-liaison psychiatry and its psychosomatic research tradition are powerful allies that have already established a beachhead.) This is the point to underline: the biopsychosocial paradigm fits the intellectual needs of the primary care disciplines, offers practical strategies for their academic development, and has the further virtue of transferring some of the weaknesses—such as the lack of

training of primary care clinical teachers in biomedical research—into potential strengths.

### Social Uses and Meanings of Illness as a Research Area

To illustrate these points briefly, it is appropriate to address a problem that should be of special interest: the social uses and personal and cultural meanings of illness. This subject holds considerable relevance for primary care, demands that researchers have training in social science, is particularly suitable for an integrated biopsychosocial perspective, and allows the researcher to move between practical and theoretical levels of academic work. The purpose here is to adumbrate a type of research problem that mandates level 2 research. Because this subject is a large one, it requires discussion in terms of a more manageable issue: chronic somatization.<sup>4-7</sup>

Somatization is the presentation of somatic complaints by the patient either in the absence of a medical disorder or as amplification of one, where the biomedical assessment of pathology cannot explain the degree of perceived disability and expressed complaints. Acute somatization is frequently the pathology of acute stress, with affective arousal responsible for psychophysiological symptoms in which the somatic side of the problem is amplified and the psychological minimized or denied. Subacute somatization most often involves a psychiatric disease: major depressive disorder, panic disorder, or phobic disorder. Both types of somatization respond well to psychiatric intervention.<sup>7</sup> Chronic somatization, however, is an entirely different kind of problem, one much less responsive to standard psychiatric treatment. Here somatization has become chronic illness behavior, a sickness career.<sup>8</sup> Even though it may be possible to make a psychiatric disease diagnosis, providing effective treatment for the disease frequently will not end the chronic illness behavior.

In chronic somatization, of which chronic pain syndrome is a leading example in the United States, interpersonal and institutional uses of the sick role, along with its personal and cultural meanings, are commonly the major reasons for the persistence of disability. For example, headaches

or low back pain may function to change jobs, get time off from work with compensation, manipulate spouse or children, sanction life failures (in school, career, love), legitimate dependency needs, discharge anger, and so forth. Illness meanings may be unique to the individual, shared in the family (and a result of family problems or a maladaptive way of coping with such problems), or hold culturewide significance. Neurasthenia among Chinese, one of the most prevalent outpatient diagnoses in China, is an especially common example of the last.<sup>8</sup>

Astute clinicians probably intuitively recognize at least the cruder of these illness uses and meanings, but how can they be systematically studied? Rarely will they be disclosed by questionnaires. Patients are often unaware of these aspects of illness, some of which may hold unconscious significance for the individual (unacceptable dependency needs, passive-hostile behavior) or be unacknowledged social fictions. An illustration of the latter is financial gain from illness which, because it runs counter to the moral prerequisite of the sick role that the sick person must want to get better, the patient cannot state, even if he or she has insight into the situation, because to do so would be to brand him or her a malingerer and therefore no longer legitimately sick. For the same reason, structured interviews with patients, even those conducted by experts, may be unavailing, especially when the chief significance of illness is not psychological, but social. Even the uncovering of psychodynamic significance may be a difficult, lengthy, and uncertain process involving what amounts to the development of a privileged psychotherapeutic relationship with the patient.

In the face of such problems, a primary care researcher might quite reasonably conclude that this subject, though of potentially great clinical importance, cannot be researched (ie, studied scientifically). But this would be wrong. Social science methods are the appropriate ones for this project and range from ethnography to attribution research methodology. Ethnography, the core methodology of anthropology, is systematic description of both qualitative and quantitative types. Quantitative ethnography includes various scaling techniques, ethnoscientific eliciting frames, sociolinguistic instruments, and measurement of time, space, change, and other coordinates of behavior and communication. Qualitative

description, taken together with various quantitative measures, can be a standardized research method for assessing validity. It is especially valuable in studying social and cultural significance, eg, illness beliefs, interaction norms, social gain, ethnic help seeking, and treatment responses, and it is the appropriate method to describe the work of doctoring.

Physicians tend to be negatively predisposed to qualitative ethnography, since it lacks the numerical indices and statistical values that they associate with "science." But this perspective is erroneous. Qualitative ethnography is a well-developed social science method that is especially useful for studying meanings. As do all research methodologies, it needs to be systematically learned along with standards for assessing appropriate and effective use. Description is a perfectly acceptable scientific methodology in ethnology and in animal behavior studies, astronomy, archaeology, and gross and microscopic anatomical studies. Increasingly, there are ways of quantitating observation, as in the clinically applied medical anthropology explanatory model and illness problem techniques,<sup>2,4</sup> but the important point to make is that quantitation and statistical assessment per se do not a science make. If the ethnography of meaning is not legitimated in primary care research, even though it is legitimated in anthropology, sociology, and social psychology, then meaning will not receive a scientifically appropriate assessment in primary care. Attribution research in psychology, survey research in sociology, and ethnoscientific studies in anthropology are quantitative approaches to meaning to which statistical evaluation can be applied. But these techniques are, for the reasons cited, less appropriate to the study of the symbolic meaning of chronic somatization than ethnography and psychodynamic exploration, or interpretive sociological and historical inquiry, for that matter.<sup>9,10</sup>

In a study of chronic somatization in China, the author used all four of these qualitative research approaches to supplement quantitative clinical description and psychiatric rating scales so as to decipher illness meanings.<sup>8</sup> The upshot was documentation that, though most neurasthenia patients studied in Hunan suffered from major depressive disorder, their chronic somatizing illness behavior did not end when their depression was treated with antidepressant medication. The reason for this

was that almost three fourths were employing their illness to change work and gain leverage over the Chinese work-disability system. Here ethnography provided crucial information on the institutionalization of somatization and its immense social structural significance that completely altered the research understanding of the data.

Applying ethnography, then, forces the researcher to grapple with basic social science questions ranging from what constitutes validity and reliability to the critical examination of hypotheses concerning social behavior and its determinants that provide primary care studies with more rigorous evaluation of ideas than is forthcoming from many clinical and health services research studies. Medical anthropology and sociology have already developed critical discourses on stress, behavioral deviance, social supports, family structure and function, help seeking, illness behavior, sick role, and many other social dimensions of health and sickness that offer the primary care researcher more than just researchable variables. These social science discourses are frameworks for interpreting research data, integrating them with major bodies of findings and analytic concepts for making sense of findings, generalizing data-based ideas within wider intellectual contexts, and providing them with established standards of academic criticism. That is to say, learning medical anthropology and sociology is much more than learning how to use certain methods or tests. It is learning a way of handling concepts, systematically thinking through problems, creating a context of criticism for one's work, and linking it to core concerns in social theory. Indeed, this is the way to expose inchoate theorizing in primary care to systematic academic criticism so as to generate a robust academic discourse that is distinct from, yet complementary to, biomedical ideas.

Hence primary care research on family functioning in health maintenance and illness should be linked to substantial social science data bases and theoretical systems for studying family structure and function, and the same can be said for the study of illness meanings, physician-patient communication, help seeking, therapeutic compliance and satisfaction, ethnicity and medical care, and a myriad of subjects relevant to primary care researchers. It is the responsibility of primary care researchers trained in social science to make these linkages. With regard to the social uses and cul-

tural meanings of illness, this means relating clinical investigations to ethnomedical and ethnopsychological studies of indigenous illness belief systems as well as to social psychological work on the use of explanations to justify social action, sociological studies of sick role negotiation and the illness labeling process, sociolinguistic studies of the language of the emotions and of interpersonal manipulation, historical inquiry into the work/disability system, and psychodynamic and cognitive behavioral research on somatic modes of communication. Placed in this context, primary care research must be simultaneously responsive both to highly pragmatic and to theoretical levels of analysis. In short, it becomes an autonomous academic medical discourse with its own relevant intellectual and scientific context.

Personal work with building primary care theory via the concepts of explanatory models, a dichotomy between *disease* and *illness*, specification of *illness experience* problems, differential practitioner and patient cultural constructions of clinical reality, and a negotiation model of physician-patient relationships follows this model.<sup>5</sup> By linking longitudinal studies of cultural influences on sickness and care with medical anthropology and other social science discourses on these topics, the author's research program both generated practical treatment strategies and elaborated a theoretical model of the structure and functions of health care systems that could be used to conceptualize primary care in American society and cross culturally. Moreover, this work has provided a direction for young primary care researchers who have worked in the research program.<sup>6,7,11-13</sup>

This particular research program, limited as it is, is only a minor and flawed example of what is needed: the creation of longitudinal research enterprises in which clinical scholars are systematically and rigorously trained to work within major social science intellectual traditions to construct mid-range theory at a high level of academic sophistication in order to better conceptualize the vast domain of clinical practice.<sup>11,13-19</sup> While this paper argues for an anthropological orientation to such work, sociological, social psychological, and social epidemiological, as well as historical, geographic, economic, philosophical, and political science, approaches also can (and should) be developed in clinical science to help create level 2 research in academic primary care.<sup>17,20-26</sup>

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