

ANTHROPOLOGICAL INQUIRY OF DISEASE, ILLNESS AND SICKNESS

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ABSTRACT

The fundamental idea for this article is a review of the theoretical discussion among experts in biomedicine and the social sciences: Arthur Kleinman, Leon Eisenberg, Horacio Fabrega, Byron Good, and Andrew Twaddle, among others; on the concepts of *disease*, *illness*, and *sickness*. The main objective is to explore the conceptual distinction between the triad from the field of anthropology, particularly on how culturally defined concepts of ill health are created. It is generally argued that the complexity of different opinions on human ailment causes difficulty in providing a clear distinction between the triad for the use among medical practitioners, social scientists, and laymen community at large. In particular the analysis reveals that most signs or symptoms of distress are reflective of sufferers' personal and cultural experiences. They are the cultural processes of *illness* and *sickness*, rather than purely understood by medical profession as *disease*. Additionally, the article demonstrates that with the effort of the experts of biomedicine and social sciences, clear definitions of the different concepts of *disease*, *illness*, and *sickness* indicate different aspects of ill health. Finally, the author focuses the discussion on a proposal to explore how the full triad can be of use amongst laymen patients, particularly in times of physician-patient interactions over ailment diagnosis.

Keywords: Anthropology, cultural, disease, illness, sickness

INTRODUCTION

In a non-medical world, people usually do not make a distinction on ill health concepts between *disease*, *illness* and *sickness*. On a fundamental level, medical practitioners and laypersons differ in their judgments and interpretations of symptoms and signs of ill health. From the laypersons' perception, these three concepts of ill health seem to mean essentially the same condition of human ailment and are often used interchangeably (Vivien & Noor 2013; Vivien et al 2013). For example, Vivien and Noor (2013) in their study on Malaysian Chinese women cancer survivors provide evidence that cancer patients or cancer survivors in most cases consider 'cancer' as a type of *illness*, rather than *disease*. In another incident, Vivien et al. (2013) observe that cancer patients refer themselves as taking 'sick leave' from official duties due to their cancer *sickness*. Similarly, both studies by Vivien and Noor (2013) and Vivien et al. (2013) indicate how cultural health beliefs play a significant role in their cancer informants' definitions of ill health concepts between *disease*, *illness*, and *sickness*. In dealing with the *disease* (cancer), the informants' personal experiences intertwined with their everyday experiences, consequently granted the usage of *illness* and *sickness* interchangeable a great deal in their normal conversation.

Conversely, in the scientific paradigm of medical world, the medical profession provides a perspective that is different from that of the laypersons. The medical practitioners

identify *disease* as distinct from both *illness* and *sickness* that only the medical practitioners are able to help in treating the *disease* (Hofmann 2002). Further, in terms of *illness* and *sickness*, medical practitioners perform different type of judgments and interpretations pertaining to patients' symptoms and signs as compared to layperson' interpretations of *illness* or *sickness*. This means to say that what do the medical practitioners consider as a 'sick condition', may not be agreeable by the laypersons. The difference of interpretations here indicates that communities' social norms and value judgments are being taken into considerations in defining *illness* and *sickness* by laypersons, but may not be so by medical practitioners (Boruchovitch & Mednick 2002).

Despite the aforesaid problems in obtaining universally interpreted valid concepts of the triad *disease*, *illness* and *sickness*, coupled with the complexity of different perspectives on human ailment. The importance of understanding laypersons' interpretations of the triad has been well demonstrated by empirical evidence (Vivien & Noor 2013; Wikman et al. 2005; Tishelman et al. 1991). Additionally, the distinction between the full triad *disease*, *illness* and *sickness* has also been elaborated, defined, and noted in theoretical discussions of medicine as well as social sciences since the 1950s (Twaddle 1968, 1994a, 1994b; Nordenfelt 1994).

However, in the review of related literature by Good & Good (1980), Kleinman (1986), Twaddle (1994a, 1994b), and Nordenfelt (1994), some significant notes have stated that *sickness*, *illness*, as well as *disease* constitute a cultural construct. The transformation of *disease* into a human experience and an object of medical attention occur through a process of attribution of meaning (*illness*), and expression of symptoms (*sickness*). The authors further proposed that the construction of a clear understanding of the triad requires the participation of several disciplines: ethnography, clinical, epidemiology, history, sociology, psychology, politics and economics, among others. Thus, the purpose of this article is to present analytical definitions of the full triad *disease*, *illness* and *sickness* from the field of anthropology. The main focus of this effort is to portray an understanding on how culturally defined concepts of ill health are created.

DISEASE, ILLNESS AND SICKNESS

In the literature, within the sociology of health and *illness*, medical sociology, medical anthropology, and other related fields, the concepts of *disease*, *illness*, and *sickness* are commonly being discussed and defined. Particularly, on the usage of the triad by medical practitioners and their patients to describe the different views or dimensions of ill health discussed between them. For instance, Wikman et al. (2005) in their study on Swedish population provides empirical evidence that most of the study informants have some sort of *illness* and complaints, with hardly any has registered with a *disease*, and even fewer had been on sick leave. The researchers further explained that there was an obvious discrepancy between reporting having a *disease* and informant's rating of general health. The discrepancies between the concepts used imply that the informants without medical knowledge tend to interpret dimensions of ill health differently as compared to medical practitioners. On the other hand, according to Kleinman (1980, 1986), the medical profession considers *disease* as alterations or dysfunction in biological and/or psychological processes; and the concepts of *illness* and *sickness* denote the meanings created by patients while dealing with the *disease* process. Further, Kleinman et al. (2006) proposed that the medical profession is primarily interested in the recognition and treatment of *disease* (curing). So paramount is this orientation that the professional training of medical practitioners tends to disregard *illness*

and its treatment. Nevertheless, according to the same authors (Kleinman et al. 2006), health as well as ill health cannot be limited to biomedical look. It requires an understanding of their biological significance as well as social and cultural significance. As such, the following theoretical discussion aims to show the impact sociocultural factors, particularly cultural beliefs, can have on patient-physician relationship and explanations of *disease*, *illness*, and *sickness*.

In the social sciences study on health and *illness*, Andrew Twaddle (1968) was first to conceptualize the triad *disease*, *illness*, and *sickness*, when he applied it in his doctoral dissertation writing. Thereafter, much of the debate on the issues of distinct meanings as well as overlapping concepts between *disease*, *illness*, and *sickness*, has become common topics in the field of social sciences (Fabrega and Silver 1973; Eisenberg 1977; Kleinman 1980; Helman 1981; Twaddle 1994a, 1994b). For instance, Fabrega and Silver (1973: 89-92) in their study on Zinacantan society in Mexico, observe that in Zinacantan, *illness* is frequently interpreted from the anthropological perspective by the Maya Indians, and it is regarded as a sign that the sufferer has sinned or misbehaved and has been duly punished by the gods. As such, treatment provided by a Zinacanteco curer often requires that he defines and explains the *illness* in supernatural and moral terms, so much so that the common medical treatment in Zinacantan involves the restoring of balance to the relationship between the sufferer with his ancestral gods by performing community folk rituals and ceremonies.

Later, Kleinman (1980: 33-34) based on his studies of health care in Taiwan, highlights a significant perspective of medical anthropology in medical knowledge concerning the cultural determining of *illness*. According to the researcher, *illness* as well as *disease* should be understood within a holistic perspective that covers all forms of therapy within the health care system of a culture. In relation to that, Kleinman notes that the Chinese culture is the chief determinant shaping the Taiwanese health care system. In Taiwan, the sick often visit more than one kind of health practitioners, ranged from self-medication within the family, to shamans operating through divination, temple priest, traditional Chinese medicine, and finally Western medicine. In most cases, the sick visit a Western doctor expecting that the Western doctors' 'magic bullet' approach, in which a shot of antibiotics given by the doctors might be able to work instantly in releasing the physical pain in them. At the same time, the same patient will also get additional advice and treatment from a shaman or religious counselor from a Chinese temple, with the purpose of getting himself cured from the *illness* completely.

Similarly, Eisenberg (1977) in his study on psychiatric disorders suggests that the social matrix of a psychotic patient, such as the patient's self-concept and his relationships with others, determines when and how the patient seeks what kind of health care, as well as his compliance with the recommended treatment. In the eyes of the psychotic patient, when medical practitioners dismiss an *illness* due to the absence of *disease* symptoms and characteristics such as physical pain or mental distress, the medical practitioners fail to meet their socially assigned responsibility. As Helman (1981) notes, a general medical practitioner who emphasizes only on the treatment of *disease* without considering the social part of the patient such as his cultural health beliefs and emotional disturbance; may cause dissatisfaction on the patient, and may lead to self-medication or consultation with other practitioners who are more willing to deal with the patient's social aspect of the complaints.

However, patients' social and cultural perspectives of *illness* as discussed by Fabrega and Silver (1973), Eisenberg (1977), Kleinman (1980) and Helman (1981), form little concern

in the Western physicians' understandings of health and *illness*. In the Western biomedical perspective, *disease* is a health problem that consists of a physiological malfunction that results in an actual or potential reduction in physical capacities and a reduced life expectancy (Twaddle, 1994a: 8). Also, under common biomedical understanding, a *disease's* etiology, symptoms and signs, natural history, treatment and prognosis are considered to be similar across all individuals, ethnic groups or cultures (Fabrega and Silver, 1973; Eisenberg, 1977; Kleinman, 1986). For example, Fabrega and Silver (1973: 1-2) state that the Western epidemiological approach frequently treats *disease* as a biomedical category that is indicated and diagnosed by specialized examinations and tests, and this Western approach is designed to make explicit the level and distribution of *diseases* such as the symptoms, prognosis, and treatment in a human community of any ethnic or cultural groups. In addition, as Helman (1981: 548) explains, the universality of the form of a *disease* is related to the biomedical model's definitions of health and normality. Most healthcare practitioners equate normality with health and view health as an almost universal phenomenon.

Disease is often seen as a deviation from the normal standard of health from which the lack of symptoms or signs indicates health. For example, the biomedical model of *disease* assumes that breast cancer in a Caribbean woman is the same as breast cancer in a Chinese woman in the United Kingdom (UK). Both women of different ethnic groups in UK present similar commonly identified breast cancer symptoms such as a lump or swelling in the breast (Waller et al. 2009). Further, Waller et al.'s (2009) findings suggested that while their cancer warning signs could be identical among the different ethnic groups, the understanding of its symptom may vary between ethnic groups, and thus causes the different attitudes they adopt in health seeking. Studies (Waller et al. 2009; Vivien & Noor 2013) show that health-seeking behaviour of patients with terminal *illnesses* generally varied among ethnic groups and is much influenced by the ethnic groups' personal, social, and cultural factors such as their cultural beliefs and socioeconomic positions. As Helman (1981: 548-549) argues, further exploration of this social and cultural dimension of the biomedical model of *disease* is better viewed from the perspective of *illness*. According to the researcher, *illness* refers to the subjective response of the patient to being unwell. It includes not only his experience of ill health, but also the meaning he gives to the experience, in which this experience consists of the emotional meanings of an *illness* to the patient, as well as the nature of the patient's affective response to his state and physical symptoms such as pain. These responses to *illness* are profoundly influenced by the patient's social and cultural background as well as by his personal traits, and these factors in turn affect the presentation of the *illness* symptoms and the health seeking behaviour of the patient.

Illness, therefore, is the patient's perspective of his ill health, of which this perspective is very different from the medical practitioner's perspective that is based on the Western biomedical *disease* model. As Frank (1995: 6) suggested, *illness* becomes the way a patient, his caregivers, family, and friends, tell his stories of ill health which are built around the patient's experience, including his current experience of ill health, his past experiences of medical discourse, information gleaned from medical discussion and the *illness* accounts of friends and family. Similar to Helman's comment on the patient's perspective of *illness*, Kleinman and Seeman (2000: 231) relate that the fundamental dimension of *illness* lies with the experience of *illness*, which is not bound by the body, or consciousness of those who are ill. According to the researchers, while biomedical model regards *disease* in terms of an abnormality of the structure or function of the organs and organ systems, a patient's *illness* experience is drawn from the patient's personal, social, and cultural experiences in life. In relation to that, Kleinman et al., (2006) and Fabrega (1972) elaborate that pre-existing

experiences of the patient then govern the patient's perception, labeling, explanation and valuation in his discomfort caused by the *illness*. The researchers' (Fabrega 1972; Kleinman et al. 2006) elaboration can be further explained through a national study carried out by Eisenberg et al. (2001).

Eisenberg et al. (2001: 348-349), in a 1997 national survey in the US, investigated patients' perceptions and consumption of Complementary and Alternative Medicine (CAM) in relation to Western medical treatment. The study findings reveal that more than half of the patients in the study partially informed or did not tell their medical doctors of their usage of CAM. In general, the patients behaved independently in their CAM treatment choices. The US patients' actions were mainly due to their own analysis of the causes of their *illness* based on their past personal and family experiences about similar types of *illness*, and thus they were able to make decision based on their cultural beliefs and confidence in CAM. The patients thought that it was not important to inform their medical doctors as the use of CAM has grown significantly in their communities. Patients' lack of disclosure in the Eisenberg et al.'s (2001) study is a common scenario among those who integrate CAM with Western medication. This is because many of those patients would be worried about the Western doctors' responses. CAMs according to the biomedical model are generally described as unproven remedies and techniques (Cassileth and Chapman, 1996: 1026-1027).

Significantly, the study by Eisenberg et al. (2001) provides evidence that is similar to Kleinman's (1975) explanation with regard to patient's *illness* experiences. According to Kleinman (1975), *illness* is culturally shaped in the sense that it is about how one perceives, experiences, and copes with a *disease* or condition. The perception, experience, and coping techniques towards an *illness* derive from patient's personal, interpersonal, and cultural reactions to *disease* or discomfort. Faced with ill health, patients try to communicate about his health problems. The manner in which he presents his symptoms, when and to whom he goes for care, how long he remains in care, and how he evaluates that care, are all affected by his cultural beliefs embedded in a complex family, social, and cultural network. Agreeing with Kleinman, Kohli and Dalai (1998) reaffirm that cultural beliefs influence patients' perceptions of diagnosis, *disease* symptoms, and perception of life and death. According to these researchers, their study on the causal explanations given by Indian women with cervical cancer in relation to their life threatening *diseases* provide evidence that these women cancer patients more often attributed their *illness* to metaphysical beliefs such as fate, God's will, and *karma*. The study findings further suggest that if the patients' cultural and religious beliefs on the causes of their *illness* were not appropriately identified by Western medical practitioners, patients' attitudes towards choices of treatment may confuse medical practitioners especially when they do not cooperate with the Western treatment as proposed by the practitioners. Patients may try to treat themselves by seeking help from their community spiritual leaders (Kohli & Dalai 1998: 115-129).

Subsequently, there is another key point as indicated in the above explanation on patient's experience relating to *illness* by Kleinman (1975) – when patients involve themselves in a wider social and cultural network of ill health, their *illnesses* are always shaped by the individual culture of the afflicted. In other words, *illness* encompasses all the ways that the patient as well as the wider social and cultural network perceive and respond to symptoms and disability. Here, Kleinman's analyses of *illness* seem to support the formation of another ill health concept - *sickness*. Similarly, within a frame of reference that is quite congruent with Kleinman's explanation on *illness-sickness*, Twaddle (1994a) refers *sickness* as a social identity. According to the researcher, *sickness* is defined as “the poor health or the

health problem(s) of an individual defined by others with reference to the social activity of that individual ... an event located in society ... defined by participation in the social system ... measuring levels of performance with reference to expected social activities when these levels fail to meet social standards ... ”(Twaddle 1994a: 11).

Hence, it is thus necessary to consider *sickness*; the third element in the discussion of an individual's well being that relates ill health to the patients' society. As elaborated earlier, *illness* is always placed within a social and cultural context, which includes patient's personal life experience, the sociocultural environment where the patient's life experience occurs, and the ways the experience is interpreted by society. In the process where the meaning and experience of patients' *illnesses* are shaped by cultural and social systems, society, on the other hand also contributes to the meaning and experience of the *illnesses* (Conrad and Barker, 2010). As Pierret (2003) notes, the social context of *illnesses* that corresponds to patients' family, economic institutions, religion, the media, and the state are then labeled as “social structure” and each part of the social structure is deemed significance in the construal of patients' *illnesses* experience. For instance, family is where ill health is first understood, and society is where others interpret the ill health of the patient and consequently the term *sickness* is labeled to it (Twaddle, 1979).

Sickness, according to Twaddle (1979) and as mentioned in the above earlier, refers to the ill health or the health problem(s) of a patient, defined by others, with reference to the social activities of the patient. Meaning that, people who are ill have a complementary socially determined role. Society, in this view, grants the ill person a role (the ‘sick role’), which provides dispensation from normal economic activity due to the reason that a sick person is not a productive member of society. Talcott Parsons, an American functionalist sociologist in 1951, originally coined the term ‘sick role’. Parsons argued that being sick means the sufferer enters a role of ‘sanctioned deviance’ of which *sickness* signifies an experience when the sick person deviates from the ‘well’ population. The sick person then carries a new role that conveys a socially recognized set of expectations and obligations, which comes with a socially recognized *disease* or *illness*. Patterns of expectations create the sick role. This role, however, is a behavioural role: the sick person is expected to engage in certain behaviour. This behaviour begins with accepting the moral responsibility to regard being sick as undesirable, as something that should be overcome as soon as possible. This acceptance is followed by the obligation to seek technically competent help, namely, that of a physician and to cooperate with him in the process of trying to get well (Parsons, 1951: 437).

In relation to patients' rights and obligations, Parsonian sick role concept recognizes that the sick individual is exempted from normal role performance and social responsibilities such as work, school or parenting. This exemption, however, is relative to the nature and severity of the *illness*. The more severe the *illness*, the greater the exemption is. And exemption requires legitimating by the physician as the authority on what constitutes *sickness*. However, the first two aspects of *right* of the sick role are conditional upon the third aspect, which is recognition by the sick person that being sick is undesirable. Thus, the sick individual has an obligation to get well. In order to fulfill the obligation to get well, it involves a further obligation on the part of the sick individual to seek technically competent help, usually from a physician. In addition, the sick individual also expected to cooperate with the physician in the process of trying to get well. It is expected that the sick individual will seek appropriate help from professionals during the process of recovery and returning to the social functioning of the ‘well’ individual (Cockerham, 2001: 156-178). In relation to the role played by physician, it is significant to point out that, in the consideration of *sickness*, the

power of the medical profession grants entry into the world of the sick (Mishler, 1981). To complement the 'sick role' concept of Twaddle (1979) and Cockerham (2001), Young (1982: 270) proposes that *sickness* is seen as a process for socializing *disease* and *illness*. Or in other words, it is a process of social construction of *sickness* that occurs in part and through medical systems (*disease*) and forms of suffering (*illness*), and later associated to society's norms and cultural values. According to Young (1982), the concept of *sickness* should incorporate the process of ascribing socially acknowledged meanings such as patients' beliefs and cultural and personal meanings, and socially significant symptoms and events; in the production of *sickness* recognized socially by the patients.

CONCLUSION

Most of the disciplines of social sciences, particularly anthropological studies, provide evidence and theoretical explanation to justify the conceptual distinction between *disease*, *illness*, and *sickness* (Helman, 1981; Twaddle, 1979; Kleinman et al., 2006). It is clear that in most cases of *disease*, they are accompanied by *illness*, caused by personal psychological, social, and cultural responses to the *disease* process. However, these responses may vary among individuals, groups, and cultural units (Helman, 1981: 550). For example, members from the same community, faced with similar episodes of *disease* may vary markedly in the symptoms they complain of and in how the *disease* is to be treated (Chang & Li 2004: 42-44). Within the close relationship between *illness* and *disease*, society acts to influence *illness* experience. Society acknowledges some *illnesses* such as common cold, cardiac conditions and cancer and grants special benefits such as medical leaves to patients experiencing those *illnesses* based on advice from medical institutions in each society. This is then represented by a new status of the patients – 'sick role' - patients may be exempt from occupational work, schooling, household chores, or other obligations of 'well' individuals. As propose by both Parsons (1951) and Cockerham (2001), individuals who have fallen ill are not only physically sick but adhere to the specifically patterned social role of being sick.

Thus far, the theoretical complexity discussed in relation to the distinction between *disease*, *illness*, and *sickness* in this article appears to be of significance in healthcare practices and in the social sciences. Few have come forward to discuss the triad for usage of laymen. Does this mean, then, that it is impossible to give a clear-cut definition for the laymen's understanding, or it is insignificant for laymen to differentiate the concepts on a daily usage? Henceforth, future study should explore how the full triad *disease*, *illness*, and *sickness* are of use amongst laymen patients, particularly in times of physician-patient interactions over ailment diagnosis.

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