CREATIVE CONCEPTS

Can anthropology improve our care of inherited cardiac arrhythmias? A modest proposal

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Calls for greater attention to sociocultural aspects increasingly demand that a more individualized, context-conscious approach become part of "personalized medicine." Today, cultural factors are considered crucial to issues ranging from acceptance of diagnosis to choice of treatment, and compliance with pharmacologic therapy, and cultural competency has become a fashionable term for clinicians and policy makers. However, as argued by Kleinman and Benson,[1] no one has yet been able to define the term precisely enough to operationalize it in clinical training and best practice standards. The present analysis makes a case for increased involvement of sociocultural anthropology in a personalized and culturally aware practice of clinical medicine, focusing on inherited cardiac arrhythmias as a particularly suitable paradigm.

The domain of sociocultural anthropology

Anthropologists have often been concerned with health and healing, and the subdiscipline of medical anthropology deals with both the understanding of illness in different cultures and the way biomedical knowledge and medical practices are experienced worldwide. The sociocultural approach attempts to reach beyond the biologic layers defining health and illness in order to understand the context within which a meaning is attributed to both concepts. Thus, anthropology, looking at the relationship between beliefs and practices, cuts across different levels of analysis, providing a unifying view of the clinical, psychological, and social levels experienced by individuals in relationship with significant others (Figure 1).

With few exceptions, there has been surprisingly little communication and exchange between clinical medicine and medical anthropology, and a sort of reciprocal suspicion has made it difficult to elaborate the productive cooperation required to improve patient care and experience. Yet, scientific knowledge often exposes the limitations of universal, one-fits-all western-centric guidelines. A fitting example of a field that would greatly benefit but has seen little attempt to apply anthropologic ideas or even cultural competency is that of familial sudden death derived from inherited cardiac arrhythmias.

An anthropological view of familial sudden cardiac death

The condition defined as sudden unexplained nocturnal death syndrome (SUNDS) is experienced, understood, and represented in very different ways across cultural contexts. In Asia, where it is endemic, it is traditionally known as *bangungot* (from the words *bangun* "rising" and *ungul* "moaning," a word also used to mean "nightmare") in the Philippines, *lai-tai* ("died during sleep") in Thailand and Laos,[2] and *pokkuri* ("sudden unexpected death at night") in Japan.[3,4] The folk explanation for *bangungot* in the Philippines is that the victim often goes to bed after a full meal, experiences nightmares, and loses control of his/her body, then, if unable to regain control by wiggling a toe or finger or being woken up by someone, may eventually die during sleep.[5] The Ilocano, one of the country's ethnic groups, attribute it to the attack of the *batibat,* a fat female demon who takes revenge for the cutting of trees by sitting on sleeping men's faces and suffocating them.[6]

SUNDS in Thailand and Japan appears to genetically and clinically overlap Brugada syndrome, a relationship that seems likely but has not been fully established in the Philippines.[7] However, the Filipino anthropologist Michael Tan[8] argues that the overlap with Brugada syndrome does not provide all the answers about *bangungot* and similar folk illnesses. He maintains that not only should biomedical research "look for its possible overlap with other cardiac problems, sleep apnoea and nutritional disorders," but it also should consider it as an idiom "through which individuals and societies can talk about particular feelings and opinions," specifically "distress and anxiety coming from being away

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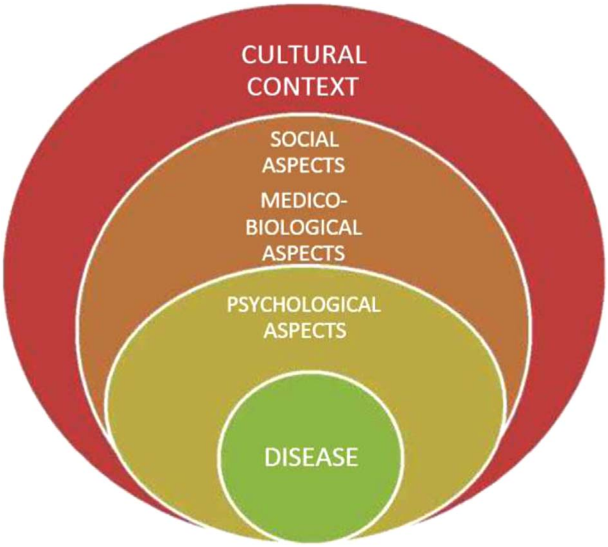

Figure 1 Aspects involved in the illness. At the core is the individual experience of the disease, entangled with the increasingly general psychological, social and medico-biological aspects. All of these are situated within the cultural context, which constitutes the object of anthropological study.

from home." Indeed, *bangungot* appears to be more common among expatriate Filipino and Thai workers and Hmong refugees from Laos.[8] However, in contrast to Tan, it could be argued that workers abroad tend to belong to the category mostly affected by Brugada syndrome—males between 20 and 40 years old.

Guidelines: A constructive critique

The European Society of Cardiology[9] recently issued guidelines on Ventricular Arrhythmias and the Prevention of Sudden Cardiac Death, widely considered a gold standard for management. Although they consistently follow a consensus document compiled by heart societies from North America, Europe, and Asia-Pacific,[10,11] the guidelines make no mention of cultural aspects or of any advantage that a context-based approach may bring to cultural competency. For example, Section 3.2 on "Autopsy and Molecular Autopsy in Sudden Death Victims" states that "an autopsy is recommended to investigate the causes of sudden death and to define whether SCD is secondary to arrhythmic or non-arrhythmic mechanisms." Although the medical rationale is undisputable, an anthropologist could object that some religions or cultures might oppose the performance of an autopsy, for example because of the requirement for post-mortem body integrity in Japan or the delay it might cause to the funeral in Malay and other Muslim cultures. Given the stigma attached to sudden death, which is seen as the effect of sin or some blemish characterizing the family (eg, in Chinese culture,[12] but also commonly seen in Mediterranean areas), relatives may resolutely oppose any further investigation on the deceased or on the pedigree.

Similar concerns apply to the recommendation that "targeted post-mortem genetic analysis of potentially disease-causing genes should be considered in all sudden death victims in whom a specific inheritable channellopathy or cardiomyopathy is suspected" (p. 8).[8] The scenario implies additional ethical issues regarding the relatives' right not to know, an individual choice that is heavily influenced by cultural aspects. In this regard, the pragmatic approach of the guidelines endorses a western mentality, seeing familial sudden death as a strictly medical problem whereby knowing and publicly sharing knowledge is the first step toward a solution. Although the guidelines mention that "the 'right not to know' and the possibility to decline molecular screening should be included in any pre-informative communication with the relatives," this option is clearly presented as a less preferable one. The implicit cultural assumptions are aptly shown by a sentence on the same page: "identification of the cause of an unexpected death provides the family with partial understanding and rationalization of the unexpected tragedy, which facilitates the coping process and allows an understanding of whether the risk of sudden death may extend to family members." The guidelines assume that relatives of victims of sudden death would be willing to disclose clinical history and other family information. However, that will prove difficult under conditions in which stigma or a sense of guilt is associated with sudden death but also, for example, in women with the *BRCA* mutation who are affected by breast cancer.[13] In certain cultures a direct and unfiltered request for sensitive information may be regarded as indelicate or downright offensive, resulting in a negative response or attitude, or it may be ineffective if the person asking the family is not aware of family relationships and roles (eg, if the patriarchal role is neglected).[12] Even the idea of ethics itself is relative, as the values informing behavior may vary between cultures and through time in the same culture. This may become particularly evident when discussing aspects such as end-of-life options or prenatal diagnosis and therapeutic abortion.

Section 3.4.2 of the guidelines show a concern for nonclinical aspects, such as the "psychosocial needs of these patients and their families," stating that "they should be evaluated and a multidisciplinary approach within specialized centres should be followed." The same applies to Section 4.6, which discusses the "psychosocial impact of implantable cardioverter defibrillator treatment" (p. 23).[8] However, no mention is made of the impact of cultural aspects on the meaning individuals attach to their psychological status or to the experiences of illness and death. In Japan, for example, traditional culture clashes with the definition of brain death, resulting in resistance to organ donation from deceased individuals for transplant.[14] Perception of quality of life and acceptance of invasive approaches, such as an implantable cardioverter–defibrillator (ICD), are also dependent on culture. For example, in North American societies, which rely on self-sufficiency, physical fitness, and a proactive mindset, quality of life will be strongly impaired by limitations imposed on physical activity and an ICD will be more easily accepted, compared to a more fatalistic approach observable in many European countries (including Italy), in which a device is often seen as an impediment and athletic competition is less important.