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Explanatory Models of Illness May Facilitate Cultural Competence in Genetic Counseling

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I am writing in response to the December 2011 issue of the Journal of Genetic Counseling which contains a number of original research papers on diversity and cultural competence. As one of the pioneer genetic counseling students in the Philippines, I am required to take a medical anthropology course which aims to provide us with an increased awareness on the various cultural understandings about the perceptions regarding disease occurrence. These lecture modules are an important component of the curriculum considering that among the 7,107 islands of the Philippines, several ethno-linguistic groups are represented and each has their own unique cultural identity.

In the Philippines, culture plays a powerful role in shaping the people's understanding of what is normal and deviations from normal, the latter often attributed to supernatural and mystical retributions. Acknowledging the already existing folk understanding and perceptions about the cause of their illness is important prior to explaining its probable genetic etiology. Conveying the biomedical explanation is indeed a challenge given the field of genetics is relatively new and the majority of the population have a minimal (even non-existent) basic understanding of genetic terminologies. Thus, being culturally competent is a gargantuan responsibility for us as future genetic counselors to ensure effective care delivery despite the cultural differences that initially exists between us and the patient (Winkelman 2009).

I agree with Warren's comments that cultural competence, as a concept, is easier to teach than to practice (2011). It does not occur overnight or during one genetic counseling session,

rather, it is a process that is unique from one counselee to the next. Cultural competence is a part of a spectrum which spans from cultural awareness to cultural proficiency (Winkelman 2009). Cultural awareness is the understanding that there are cultural differences between the counselor and the counselee. Beyond cultural awareness is cultural sensitivity wherein the counselor has the ability to appropriately respond to cultural differences. In the middle of the spectrum is cultural competence which is the ability to deal effectively with every culture. The highest in the spectrum is cultural proficiency which is the ability to transfer the skills in dealing effectively with culture to another individual. This spectrum can be seen as a ladder-type model wherein awareness needs to be developed first prior to going to higher stages.

One method that can be used by genetic counselors to develop awareness and sensitivity to cultural differences is the use of explanatory models of illness. The explanatory models (EM) of illness provide a focused explanation of the patient's understanding of his/her illness (Winkelman 2009). Furthermore, EMs of illness elucidate the perceptions and beliefs of the patients about their illness and the different values and meanings the patient associates with the disease (Kleinman et al. 1978). Exploring the EMs of illness is an important step to ensure that care providers and the patient are working on the same contextual framework, thus, preventing miscommunication between the two (Winkelman 2009).

There are a number of frameworks by which EM can be elicited from the patient, but the most commonly used is the framework of Arthur Kleinman. He formulated the EM framework by asking eight questions namely: (1) What do you think has caused your problem? (2) Why do you think it started when it did? (3) What do you think your sickness does to you and how does it work? (4) How severe is your sickness and will it have a short or long course? (5) What

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kind of treatment do you think you should receive? (6) What are the most important results you hope to receive from this treatment? (7) What are the chief problems your sickness has caused for you? And (8) What do you fear most about your sickness?

I would like to share an example of an inherited condition, Brugada syndrome, that may be better understood in a cultural context using the explanatory model of illness. Briefly, Brugada syndrome is a complex disease of the electrical conduction system of the heart characterized by ST-segment elevation in the right precordial ECG leads (ie. V1 to V3) (Wilde et al. 2002). It is a hereditary condition which follows the autosomal dominant pattern of inheritance with low penetrance. The *SCN5A* gene, which codes for the alpha-subunit of the sodium channel in the heart is the only gene so far that is implicated in this condition (Antzelevitch et al. 2005).

In many parts of Southeast Asia, Brugada syndrome comes in different names which may be an evidence of cultural influence to the understanding of the condition. In Thailand, it is known as the *lai tai*. The Hmong people in Viet Nam call it *dsub tuong*, while it is known as the *pokkuri* death syndrome in Japan (Nakajima et al. 2011). In the United States, it is known as the Sudden Unexplained Nocturnal Death Syndrome (SUNDS) which was first reported in 1977 when the Center for Disease Control and Prevention recorded a significant number of sudden death among South East Asian refugees, majority of which are males who are otherwise healthy and without any pre-existing cardiovascular conditions (Baron et al. 1983). In the Philippines, it is known as the *bangungut* (Sta. Cruz 1951; Nolasco 1957; Aponte 1960).

As part of our medical anthropology module, I conducted preliminary informal interviews to a convenience sample of ten informants. I did the interview at my workplace and the sample consisted of office clerks and utility workers. The aim of the interview is to provide insights to the popular explanation of *bangungut*. My opening question to them was “*Ano ang alam ninyo sa bangungut?*” (What do you know about *bangungut?*).

Based on these interviews, I found out that the meaning of *bangungut* has evolved through the years. Early literatures have equated this with SUNDS. If that is the case, then we expect there would be no survivors. However, if you talk to people in the Philippines about *bangungut*, they would tell you that they have personally experienced it or they know someone who has it. Some experienced it more frequently than others. Some equate *bangungut* with nightmares while a majority would point out that it is entirely different from dreaming or nightmares. It is frequently characterized by chest heaviness and limb paralysis. There is also a conscious struggle to free oneself from the paralysis. The remedy, they told me, is for the victim to at least move the tip of his/her fingers.

Published literature states various etiologies as the cause of *bangungut*. Some reported that it is associated with

acute pancreatitis, while others proposed that one’s diet is a contributing factor since Filipinos are fond of salty foods (Nolasco 1957). In addition, increased anxiety has been thought to predispose certain individuals to experience *bangungut* since a few people have stated that they experience it when they sleep in small rooms (possibly claustrophobia). Interestingly, one informant reported that her sister experiences *bangungut* only when she sleeps in a double-deck bed. Another interesting factor that was brought up by one of my informants is that eating noodles before sleeping allegedly increased the risk of having *bangungut*.

Tan (2008) offers insights as to the sociological perspective of *bangungut*. He reported that *bangungut* is often seen to be symbolically similar to soul loss, the two being used to represent fear of “losing control over one’s self”. Heavy meal at night is one of the more popular laymen explanations for *bangungut*. Tan specifically discussed *bangungut* as a form of “social control against overeating” (2008). The higher prevalence among males is seen as a result of higher social expectations from among them. Hence, *bangungut* is seen here as a form of ‘giving up’ thereby liberating oneself from such social expectations. As a social phenomenon, *bangungut* has not been well documented in published literature and no comprehensive qualitative and/or ethnographic studies have been done.

In the Philippine setting, the example of *bangungut* further illustrates that the biomedical model of illness is not adequate to explain the intricacies of a genetic condition especially if there is already a strong cultural influence. The varying social and cultural definition of *bangungut* is diffused and each person has its own unique explanatory model of the condition. It is anticipated that as more in-depth investigations are made, the more variations in terms of explanatory model will surface. It is, therefore, important that the genetic counselor is vigilant in exploring each patient’s explanatory model and use these as take-off points during the progression of the genetic counseling session.

As a methodological tool, the explanatory model of illness provides the capacity to become culturally competent as it allows us to obtain crucial information on the patient’s understanding and perception of genetic risks, occurrence and recurrence risks, and the overall acceptance of the disease. Shared passionately with my fellow genetic counseling pioneer student cohort, cultural competence is indeed an important and necessary skill that is necessary in training in order to expand the provision of genetic counseling services in our country.

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