

Immigrant and Refugee Explanatory Models of Chronic Disease: Provider “Learning Up” for Culturally Responsive Care

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Immigrant and refugee populations in North Carolina bring with them traditionally based explanatory models (EMs) of disease that influence health care interactions. Providers who encounter these models are often challenged with how best to leverage them for prevention outreach and care. Participation in “learning up” opportunities increases provider awareness and capacity for cultural responsiveness when dealing with immigrant and refugee clients.

In Anne Fadiman’s acclaimed book, *The Spirit Catches You and You Fall Down*, a refugee family from Laos clashes with the American medical system over the care of their epileptic daughter, Lia [1]. Both the parents and Lia’s pediatricians want what is best for the child but carry out their obligation based on distinctly different and culturally entrenched models of disease causation and management. Lia’s parents perceive her epilepsy (or *qaug dab peg* in Hmong language – which roughly translates to “the spirit catches you and you fall down” in English) as a condition caused by her frightened soul fleeing and wandering off from her body [1]. Her doctors, on the other hand, explain her condition as a case of repeated seizures resulting from the misfiring of cerebral neurons. Managing the condition requires seeking advice from a shaman and animal sacrificing to appease the Gods in Hmong tradition versus consultation with neurologists and careful administration of anticonvulsants per the biomedical model. Misunderstandings and frustration ensue as neither side understands or endorses the interventions of the other. Sadly, Lia’s health worsens, finally leaving her in a vegetative state. While this story and its events unfold in Merced, California, it is a familiar storyline that illustrates a common scenario that can happen when North Carolina’s ethnically diverse immigrants and refugees encounter the state’s health care system.

For more than two decades, North Carolina, a region known for agriculture, southern hospitality, and civil rights activism, has seen a steady increase in the arrival of diverse foreign-born individuals and families [2]. This has included a large in-migration of Latino individuals, many of Mexican origin, and resettled refugees fleeing war and conflict in Eastern Europe, the Middle East, Southeast Asia, and Africa

[2]. In fact, foreign-born individuals make up approximately 8% of North Carolina’s population [3]. Many immigrant (legal and undocumented) and refugee arrivals are concentrated in the state’s urban centers or sub-regions such as the Triangle and Piedmont Triad [3, 4].

Global trends show a rapidly rising prevalence of non-communicable or chronic disease conditions such as hypertension, diabetes, and cancer in regions where many of these immigrant and refugee populations reside [5]. In fact, chronic diseases are common among adult refugee arrivals to the United States [6]. For those with longer length of stay, Mexican/Central-American and Caribbean immigrants bear the highest burden of diabetes and obesity, and Southeast Asians have the highest prevalence of hypertension [7]. This underscores the likelihood that similar immigrant and refugee populations in North Carolina are also presenting with one or more of these chronic conditions. Even when immigrants and refugees arrive in fairly healthy condition, their risk for these chronic conditions increases with increasing length of residence in the United States due to changes in dietary practices, social isolation, and economic stressors [6].

For providers who work across the spectra of prevention and primary care, these chronic health issues, coupled with the diversity in traditional health beliefs and practices, represent complex and often daunting challenges. Our American public health and medical systems must figure out how to efficiently and effectively deploy resources for culturally appropriate prevention outreach and primary care. This is no easy venture, for as with Lia’s case, many immigrant and refugee individuals and their families operate within explanatory models (EMs) of sickness and disease that tangentially, if at all, align with American systems that are primarily organized around a Western model of delivery. Since these populations make up a growing percentage of

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the racial and ethnic minority populations being served, they must receive quality care in a manner that is "...responsive to diverse cultural health beliefs and practices..." per the National Culturally and Linguistically Appropriate Services (CLAS) Standards [8].

Explanatory Models (EMs) of Disease

EMs, for purposes of this commentary, refer to concepts, understandings, and explanations of illness and disease conditions, and the consequences and outcomes of having those conditions [9]. According to Kleinman's framework, EMs involve beliefs and attributions of illness causation and time and mode of onset of symptoms. They comprise beliefs about the degenerative processes involved with an illness, course and severity of the illness, and appropriate treatments or coping responses [9]. They are sometimes hard to immediately grasp, especially for those working within Western biomedical institutions. The lay EMs that many immigrants and refugees bring with them from their homelands can be considered "idiosyncratic and changeable" [9]. Many of these were not devised overnight and emerged out of entrenched cultural systems and models that help individuals make sense of, organize, and operate in (and even survive) the world around them.

Lay EMs of chronic conditions commonly involve conceptions of body balances, supernatural or spiritual influences, and social relationships. These drive the adoption of culture-bound healing or therapeutic practices either by themselves or in combination with conventional biomedicine [10]. For example, among adult Mexican and other Central American immigrants, hypertension and diabetes are conditions with multiple causes including *susto* (fright), which results in soul loss; *coraje* (anger or strong emotion); *ataque de nervios* (sickness of nerve; a response to stressors); and *mal de ojo* (evil eye) [11]. Certain types of cancers have lay EMs that may be unfamiliar to Western medical providers as well. Breast cancer, for example, is seen in some Latin American cultures as a result of unused milk in the breast when breastfeeding ceases or a blow to the breast area [11]. Therapeutic strategies include acquiring herbal remedies sold at *botanicas* such as *sapodilla* and *ajo* (garlic) for hypertension and *governadora* leaves which are boiled and consumed as tea for stomach aches and arthritic pain, and consultation with *curanderos* (folk healers) who can intervene in physical and spiritual dimensions [11, 12].

In Southeast Asian immigrant and refugee communities, traditional medicine use is common, often in conjunction with Western medicine. Traditional medicine in these communities is based on the theory of Dong Y and refers to outcomes as a result of Qi (energy) [12]. Under Dong Y, illness and disease result from humoral imbalance. For example, imbalance can occur between "Am" and "Duong" forces (yin and yang) [11]. These forces are part of belief systems in Vietnamese and other Southeast Asian communities [11]. The imbalance is thought to result from poor fam-

ily relations, dietary changes, and weather conditions. The net result is a disrupted physiological state such as blood flow disruption. This manifests as hypertension and other chronic conditions. Balance can be restored through ingestion of medicinal herbs; coin rubbing (variously known as *kol*, *cao gio*, or *khout lom*), a practice of rubbing the skin with a coin to remove toxins and relieve blood congestion; cupping (*giac*), in which heated glasses are inverted and placed on the skin to pull out bad toxins or forces; pinching, where the eyebrows and nose are pinched to relieve headaches; acupressure or massage; and protective tattooing [11, 12].

Among continental African immigrants and refugees, the use of traditional medicine such as herbal teas for relief from illness is quite popular. Traditional healers are often consulted for healing and religious ceremonies to deal with supernatural causes of diseases. Some individuals also wear amulets (*kitab*) for averting spirits and spells. African immigrants and refugees will often combine or alternate these remedies with prescribed medications [11, 12]. Given this plurality of EMs and associated treatment modalities, as immigrants and refugees encounter the US health systems, careful attention and consideration should be paid to them in all consultations with providers, whether in the ER, during hospitalization or primary care related visits, or in public health outreach.

The "Learning Up" Approach to Provider Responsive Care

The actual time that immigrant or refugee individuals typically spend in the care of providers or interacting with the American health system, compared to other integration and survival activities in their lives, is fairly low [13]. Furthermore, although area health institutions have interacted with foreign-born clients for decades, interactions and experiences with distinct newcomer populations may be minimal. In the absence of structural systems and formal repositories of strategies for engagement, there remains a steep learning curve for providers on how to connect with immigrant and refugee patients and build empathetic relationships within their communities.

To do so, providers must critically assess their own readiness as a benchmark for quality, culturally competent care. They must concern themselves with questions like, "What do immigrants and refugees see and experience that indicates I am a culturally-responsive provider?"; "What do (or must) I do to prepare myself to care for these patients?"; "What is (or will be) my demeanor when I encounter new patients with alternate EMs of disease, beliefs, and behaviors?"; and, "What does my practice environment and institution do to help me fulfill my obligations of quality care?" While it is almost impossible for providers or institutions to have a thorough grasp of all permutations of EMs and associated practices, they must at least be committed to "learning up" (reflection-in-action learning through intentional community encounters and immersion) to better connect

with and understand the EMs and practices of their immigrant and refugee patients [14].

Since 2011, my colleagues and I have collaborated with students, community advocates, and immigrant and refugee stakeholders to implement opportunities for “learning up” and bridge building with our regional health system. We have organized a number of small meetings with medical care providers including a moderated discussion between Montagnard immigrant and refugee community paraprofessionals (ie, those who were trained as doctors in Vietnam) and American doctors. The purpose was to 1) discuss chronic health problems, patient education needs, and adherence issues; and 2) come up with strategies for better patient outcomes and reduced costs to families. We have also organized chronic disease (hypertension and diabetes) prevention education and screening events in Montagnard and Bhutanese Southeast Asian immigrant and refugee community venues. We were deliberate in inviting doctors and nurses who routinely encountered individuals from these communities in their practice settings. During the events, we created privacy stations where we hosted the medical professionals for “one-to-one consults” with middle aged and older adult community members previously diagnosed with hypertension and/or diabetes. With the help of interpreters, doctors were able to spend the time for patient education, discussing disease management challenges, medication adherence issues, and other health concerns. In exchange, these adults and accompanying family members spoke candidly about their struggles in the context of ethnic and tribal affiliations and traditional health practices. These opportunities are illustrative of a “learning up” approach. By changing the usual script of provider-dominant relationship to a provider-community partnership, this approach enables more sophisticated cultural understanding and increases provider ability to act as an advocate for refugee and immigrant patients.

Final Thoughts

Providers and the institutional models within which they operate must take more than the usual cursory steps, such as introduction to care services with limited sustained follow-up, when it comes to caring for immigrants and refugees. Providers and their institutions must continue to build relationships with the immigrant and refugee communities that comprise their patient population. Further, there must be continued efforts to correct any misalignment of provider assumptions and expectations of how immigrant and refugee patients should think, decide, consent, and act when encountering clinical disease explanations and treatment recommendations. These assumptions and expectations often overlook EMs and the individual’s perceptions of encounters with an unfamiliar, complex, and very expensive American health care system. At the same time, providers should avoid applying sweeping generalizations about cul-

tures as patients’ EMs may differ based on regional or subgroup affiliations. Instead, providers and their institutions should either begin or continue to engage with community “learning up” opportunities and thread these together with ongoing clinical encounters involving distinct EMs of disease. This creates collective and systematic awareness which, when institutionalized, facilitates a supportive infrastructure for providers and immigrant and refugee patients alike. This provides a framework for culturally empathetic and quality patient care. **NCMJ**

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