

**Commentary: The Hmong and their Perceptions about Physical Disabilities:
An Overview and Review of Selected Literature**

By

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Abstract

The Hmong are one of the fastest growing populations in Central California. Hmong refugee families arrived in Fresno in the late 1970s facing a variety of challenges regarding their traditional health beliefs and the customs of mainstream Western biomedicine. Differing and sometimes conflicting perceptions about physical disabilities have resulted in painful misunderstandings between Hmong families and Western health care providers. The aim of this paper is to present a review of some of the Hmong health belief literature concerning physical disabilities in children. It also includes commentaries from those who work with the Hmong families of physically disabled children.

Keywords: Hmong, Physical Disabilities, Health Care Providers, Central California

Purpose

The purpose of this article is to review existing research and publications about Hmong perceptions of childhood physical disabilities. In this manuscript, comments from practitioners working with disabled Hmong individuals have also been included. These commentaries are intended to provide enriched information for health care practitioners and those in the behavioral sciences. These interviews are important because so little written information on this subject is readily available in mainstream professional journals.

The approach of including contemporary anecdotal evidence can update some aspects of the literature about Hmong families with disabled children and lead to further research. It can also sensitize practitioners in related fields by improving their understanding of these families in order to communicate in a culturally congruent and acceptable manner.

Methodology

There are several challenges in reviewing the Hmong disability literature. First, the literature specific to Hmong parents and their disabled children is limited. Next, study participants are often mixed in with other, very disparate groups of Southeast Asians. Additionally, the Hmong can be at different stages of assimilation to their new home country. They can be newcomers, acculturated, assimilated, or a combination of stages in transition (Vaughn, 2004; Leininger and McFarland, 2006; Meleis, 1991). By the time research is published, a parent may have moved from a highly traditional mindset to a more “Western” perspective, or a personally unique blend of both. Another daunting hurdle is the lack of some congruent concepts and matching words for a specific disorder. The English and Hmong languages are vastly different “so that there are terms in English that do not exist in Hmong, and vice versa.” (Cha, 2003). It has been over three decades since the Hmong first came to the U.S.A., and now there are not only intergenerational differences, but also cultural perception differences based on acculturation and assimilation. In the process of cultural transition there are some Hmong children who speak only English and some Hmong elders who speak only Hmong. Some Hmong are literate in both written and oral Hmong and English, or illiterate in both. Additionally, there are individual differences as there are within all cultures (Yang, 2008) so sweeping generalizations and assumptions cannot be made about Hmong cultural beliefs in regards to disabled children.

Herther (2009) provides an initial citation analysis of the general Hmong Studies research literature. Herther's research identified bibliometric patterns. Data taken for this review included digital dissertations, scholarly database searches, author countries of origin, institutional affiliations, and top subjects. The author discusses her findings of this "emerging, growing, and developing" field. Although no core literature is identifiable from this study, Herther notes that there is a developing "invisible college" of researchers which include Hmong and non-Hmong. Coughlan (2007) provides an additional source of citations about culturally competent care for Southeast Asian/Asian groups from which some specific data about the Hmong can be extracted.

For the purpose of this manuscript, the key search words included: Hmong, disability, handicap, birth defect, attitudes, beliefs, physical, family, and truncated disabi*, injur*, child*, parent*. Databases included CINAHL, MedLine, PsychInfo, Pro-Quest Ethnic Newswatch, JSTOR, Anthropology Plus, Philosophers Index, America: History and Life, ATLA Religious Index, ERIC and Digital Dissertations, as well as searches through Google Scholar and MeSH. A "snowball," or "word of mouth" technique was also used to gather expert personal comments.

This manuscript is structured within the framework of the classic Health Belief Model which associates beliefs with related health behaviors. The Health Belief Model history developed as a result of the perplexing lack of response to preventive care for tuberculosis. (Rosenstock, I.M. 1974). Almost a century later, we still have many questions about how beliefs affect behavior. Although the current written literature is scant about Hmong beliefs regarding their children's physical disabilities, these inquiries can be a starting place to identify trends and related issues in a clear, culturally congruent, and respectful manner.

Overview of Disabilities

Beliefs about disabilities have changed dramatically in the United States of America. In the 1970s, families of disabled children were counseled into “acceptance.” in the 1980s, there was an emphasis on behavior training for parent and child. With the advent of the Individuals with Disability Education Act (IDEA) Public Law 99-457, practitioners and families of children with disabilities were to be treated as a partners and collaborators. However, researchers have found this focus applies more to mainstream families. Those with cultural and linguistic diversity were largely ignored. In virtually all societies, a distinction is noted between the “abled” and “disabled” person (Helman, 2007).

The World Health Organization (WHO) has classified disabilities into two lists, one of impairments of body functions and structure and the other, the domain of activity and participation. WHO defines disabilities as an “umbrella term, covering impairments, activity limitations, and participation restrictions; an impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations” (*World Health Organization: Disabilities/definition*, 2009). The Americans with Disabilities Act describes an individual with a disability as a person who “has a physical or mental impairment that substantially limits one or more major life activities; has a record of such an impairment, or is regarded as having such an impairment.” It is estimated that there are approximately 35.9 million differently abled civilian non-institutionalized people over the age of 5 according to the U.S. Census Bureau’s 2009 American Community Survey, the current U.S. total population is estimated at 307,557,747 (*U.S. Census Bureau Report: Disabled population over age 5 years*, 2009).

In spite of these official facts and definitions, people continue to struggle with how to identify those that are disabled and to articulate the appropriate words to describe a person who is differently abled. The imbedded negative connotations can reflect both personal and cultural beliefs and feelings (*Tips on writing/Americans with Disabilities Act*). WHO continues its definition stating, “Thus disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives”(Epstein et al,1997; Helman, 2007). This sentence approaches the heart of the true meaning or “definition” of people who have abilities different than others. Our world is a global community, with people moving and relocating to other countries as immigrants and refugees. People from a variety of cultural and belief systems have mindsets about the disabled that may or may not align with that of the society in which he or she now lives. This describes the situation of many disabled Hmong and other families transitioning to life in the United States.

The Hmong and Disabilities

The Hmong, a group of people who fought as American allies in Vietnam, are a fast growing minority group in Fresno, California. After the war, the Hmong lived under continued threat to their safety and health. Having a newly acquired written language with vastly different customs, beliefs and world views, their incorporation into mainstream American society has been difficult at best. Governmental agents, police, and outside authorities were sometimes mistrusted and feared by community members (Burge, personal correspondence, 2010).

According to the 2009 American Community Survey, an estimated 236,434 Hmong reside in the United States (U.S. Census Bureau, 2010). The largest groups of Hmong are clustered in three regions, Central California, Minnesota, and Wisconsin. Since this time, secondary migration has led to an increasing Hmong population in the Midwestern states and

North Carolina. The 2009 Hmong census data indicate that the Hmong population is very young with a median age of 20.5. Their average family size was reported as 5.39 (compared to the U.S. average of 3.23) and a family poverty rate of 26.9% (compared to the U.S. average of 14.3%)(U.S. Census Bureau, 2010). The U.S. Hmong were less likely to report one disability compared to the mainstream. (Asian and Pacific Islanders American Health Forum: *Hmong in the United States*, 2006). They were over-represented as having a “mental disability, self-care disability, a go-outside-home disability and employment disability” according to Reeves and Bennett’s *We the People: Asians in the United States* (2006).

The Scope of Hmong Disabilities

There is no accurate count of the number of Hmong living in the U.S. who have disabilities as described by the Americans With Disabilities Act (A.D.A.) and the World Health Organization (W.H.O.). Although over 3 decades have elapsed, the U.S. Hmong refugee demographics include many residing in multi-generational homes with strong clan affiliations and family ties. A low but improving socioeconomic status and rapid urbanization represent shifts from previous rural lifestyles in Southeast Asia. According to Yang and Mills (2008), the higher activity and traditional Hmong high fiber diet is transitioning to a more sedentary American lifestyle with its high saturated fat food diet which is often associated with disabling chronic health conditions. In Yang and Mills’ study of 79 Hmong adults in California, 64.9% reported knowing someone with a disability, of which 86.8% were family members.

Culhane-Pera, Cha and Kundstadter, (2004) observe that in the Hmong cultural context and social structure, a person with any disability may be perceived to reflect natural, supernatural, personal, and or social causes. Some disorders can be considered a gift from God or suffering caused by spiritual wrongdoing. Lee and Yuen (2003) note that perceived causes of

disabilities have been listed as falling into three major categories: a birth defect, a mad-crazy person and severe bodily injury from the war. Considering this cultural viewpoint, many more subtle disabilities may be overlooked, yet have a major impact on a person's daily life and functioning. The use of translators and interpreters and a respect for cultural influences can only support the ability to correctly diagnose the condition and identify the need for support services.

Major health issues among the Hmong population have been cited to include hypertension, cancer (nasopharyngeal, stomach, liver, pancreas, leukemia, and non-Hodgkin's lymphoma), diabetes, infectious diseases (acute and chronic Hepatitis B), maternal and child health issues, mental health concerns, substance abuse, nutrition, weight and physical activity and sudden death, according to the Asian and Pacific Islander Health Forum (*APIAHF health brief: Hmong in the United States*, 2006). Bliatout's important research in the early 1980s focused on Sudden Unexpected Nocturnal Death Syndrome (SUNDS) which affected some Hmong soon after arrival in the United States. Bliatout (1982) identified changes of diet and lifestyle and environment which were all considered as possible factors, together with war trauma, which may have triggered nervous breakdowns as well as nightmares which were seen as attacks by ghosts, and in certain cases even apparently inexplicable deaths.

Pinzon-Perez's (2006) more contemporary study of major health issues among the U.S. Hmong, also lists tuberculosis, hepatitis B carrier status, asymptomatic splenomegaly, sudden nocturnal death syndrome, post-traumatic stress disorder, injuries related to agricultural occupation, cardiovascular disease, diabetes, lower immunization rates, cancer, genetic and diet related issues. All of these disorders have the potential to cause disabling conditions that may affect long term morbidity and quality of life issues, such as the findings of a recent study of 7

Hmong patients on hemodialysis, who expressed sadness, uncertainty, fear related to life, death, dialysis, and their future (Krueger, 2009).

In *Healing by Heart: Clinical and ethical case stories of Hmong families and Western providers*, Culhane-Pera, et al (2004) provide an insightful compilation of clinical and ethical case stories of Hmong families and Western providers. This work gives those who interact with the Hmong a cultural appreciation of their beliefs in a variety of situations. Tatman's (2001) study of nineteen Hmong participants concerning disability perceptions includes a description of two general categories; first, those disabilities caused by genetics, illness, and injury and those perceived to be the result of sin and for punishment.

A well-known book which reflects the angst of cultural and medical misunderstanding is Fadiman's (1997) *The Spirit Catches You and You Fall Down*. This work describes the conflict between a Hmong family and the Western medical perspective over a serious disorder in a Hmong child. The blatant ethnocentrism sometimes associated with Western medicine was also described in *Fresno Bee* newspaper headlines in Central California: "Judge will decide fate of Hmong child caught in cultural vise" (Pulaski, 1990) and in 25 other related newspaper headlines archived from this newspaper between 1989 through 1993.

Cho and Hummer (2001) assess disability status differentials, such as work, mobility and self-care, and subgroups. These researchers include Hmong with other refugees from Laos and Cambodia in an "Other Asian" category. The inclusion of multiple ethnic groups into a single category is justified by these researchers due to the small sample sizes of each group and the findings that they had similar disability outcomes. This multiple regression analysis of the relationship between nativity and duration in the U.S. to functional disability showed an increase in reported disability associated with time in the U.S. The Hmong, Laotian, and Cambodian

cohort in the study demonstrated the least favorable disability status profiles (highest disability rates) compared to other Asian groups.

Hmong who have hearing and visual impairments face special challenges. Watham-Ocama and Rose's (2002) study of 7 Hmong families provides recommendations for culturally appropriate care and for assisting Hmong clients in overcoming barriers to their knowledge of available services. Most of the parents in this study reported limited knowledge of the policies, procedures, practices, and organizational structures of special education and all cited communication barriers as impediments to involvement in their hearing challenged child's education. Vang and Barrera (2004) suggest a process to engage Hmong parents of children with disabilities in discussing their perceptions about schools and their relationships with schools as well as classroom instruction. Other publications recommend culturally sensitive care to help families who are raising a child with a visual impairment, emphasizing that translators and interpreters are essential to ensure and enhance communication and to support children with special education needs (Kalyanpur, Harry, & Skrtic, 2000; Lee & Yuen, 2003).

Comments from Contemporary Care Providers of Hmong with Physical Disabilities.

The consistent finding that there is little available literature about Hmong with physical disabilities represents a call for researchers to examine these issues. Culhane-Pera (2001) recommends that "first we ask patients about their beliefs, values, and practices, and then we can respond to their cultural needs." Culhane-Pera (2010) notes that community based participatory action research gives people a voice in identifying and solving health problems affecting their communities.

Connie Cha, the Chief Executive Officer of a daycare in Fresno, describes Hmong families who have disabled children as at times feeling hopeless and helpless. Not only may

children with a disability be stigmatized as possibly having done something wrong in a previous life, but their entire family, siblings, and extended family may be stigmatized as well. This is because of beliefs among some that a disabled child in the family may cause “bad blood” to be passed into another generation. For this reason, the children with disabilities may at times be kept at home and not exposed to the public.

A Hmong man described parents that he was acquainted with who said that it was very difficult to take care of their disabled child. They often felt depressed and felt they were being punished by God. They felt shame and did not know where to go for help.

One of the staff members of a refugee non-profit organization commented that in her experience many of the Hmong parents of disabled children hold attitudes similar to more traditional groups in the general American population. They hide and feel shame from having a disabled child in their family. She emphasized that she has observed that the Hmong generally dearly love their children, but that parents may not know what to do or how to access support services.

Implications for Multicultural and Global Health

The assessment of currently published research concerning the Hmong demonstrates major gaps as well as opportunities for further research. We currently have very little baseline data from which to draw assumptions, which means that researchers need to find ways to learn more about this growing sector of the population. Basic qualitative, ethnographic field work can begin to provide understanding and insights, as well as address the commonplace ethnocentric viewpoint with one that also incorporates insights from Hmong culture.

Since the Hmong come from a traditional oral and story-telling history, a useful description related to the Hmong perception of the disabled is enmeshed in an analogy expressed

by the Hmong mother of a child, Pam, who has Down's syndrome and a heart defect as described in Phua Xiong's case study which is included in the *Healing by Heart* anthology (2004). Pam's mother says, "All children are not born beautiful physically. Just like a patch of cucumbers or squash, not all will be long, slender and straight. Some will be crooked, short, or be uneven. But, if you take care of the not so perfect ones well, cover them with a leaf to protect them, they will turn out all right, not so crooked in the end" (Xiong, 2004).

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