planation for the biological cause of their child's disease. This knowledge is meant both to eliminate the caretaker's fear that their child is a form of punishment and to empower him or her with knowledge to educate community members at home.

Religious leaders employed by the hospital are available to counsel caregivers and their children throughout their hospital stay. Families are free to interact as much or as little as they choose with the religious staff. Spiritual counseling is available to guests on an individual basis, and prayer and song sessions are regularly held for community worship.

CCHU strives to accommodate patients from every geographic region and tribe of Uganda and beyond. With over 80 different tribes and scores of distinct languages and dialects, CCHU employs staff that speak dozens of languages to ensure that patient caretakers can tell their child's story in their native tongue. The hospital leadership believes that of all the obstacles faced by these patients, a language barrier is one that can be eliminated from the outset. Finally, CCHU empowers patient caretakers, and women in particular, by equipping them with 'income-generating' activities. A section of the hospital is charged with training women to make beaded necklaces from scrap paper, and selling their work in local markets. Such activities are designed to provide patients with a small source of income and to reduce their dependence on potentially unreliable partners or family members.

This multifaceted approach to caregiving makes CCHU unique among Ugandan hospitals. It is only when patient caretakers are empowered with this knowledge and skill-set that these patients have a fair chance at living meaningful lives.

Accurate diagnosis of DWC is the first step in treating DWC-associated hydrocephalus. Failure to do so may result in progressive hydrocephalus, cerebral cortical compression and atrophy, irreversible macrocephaly, herniation, and death. Recognition of signs and symptoms of hydrocephalus should prompt neuroimaging to define the etiology of hydrocephalus, DWC, or otherwise. Using the criteria reported in this manuscript, we believe three entities along the DWC continuum can be accurately diagnosed using CT scanning instead of MRI. Patients can then be offered a variety of surgical treatment options with the goal of resolving hydrocephalus.

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Language of the Heart: A Student's Perspective on Congenital Heart Defects and Volunteering

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Lan Xiao Hua is a 13 year old girl from Gansu, China. She had Ventricular Septal Defect, a hole in her heart's right ventricle. Doctors said she would be able to live to approximately 20 years of age. Xiao Hua's family knew about her congenital heart disease (CHD) since she was 7 years old, but with the humble living they made coaxing wheat from the dry, parched land of Gansu Province, the necessary surgery expenses would have required 10 years' worth of their income.

Xiao Hua's condition is not untreatable. Rather, CHD requires what is considered one of the simpler cardiac surgeries. Had Xiao Hua been operated on earlier, the chances of a successful surgery would have been almost 99%. After the surgery, she would have been completely normal, with few lingering symptoms. Instead, without the necessary surgery for CHD, Xiao Hua was easily exhausted by the simplest of everyday activities, such as walking. Her lips were tinted blue whenever she did any work. Even breathing was painful for her. Xiao Hua was more susceptible to transmittable diseases and caught colds frequently, a symptom of poor blood circulation. She was also shorter than other 13-year-old girls because her faulty heart contributed to stunted growth and development. Xiao Hua desperately needed the heart surgery, but she didn't have the resources needed to obtain treatment.

Lan Xiao Hua's plight is not unusual. Congenital heart defects (CHD) are a leading cause of child mortality both worldwide and in the U.S. According to the American

Heart Association, CHD is one of the most common birth defects in the U.S. (American Heart Association, 2011). Nearly two times more American children die from congenital heart disease annually than those who die from all other forms of childhood cancers combined (Children's Heart Foundation, 2009).

Whereas approximately 1% of newborns suffer from congenital heart defects in the United States, that percentage is roughly 6% in the province of Gansu, China (Gao & Yue, 2005). Many families in industrialized countries are able to afford reconstructive surgery for CHD shortly after birth. But in China's Gansu Province, the cost of an approximately 30,000 RMB (or approximately $4000) operation is unattainable for millions of poverty-stricken Gansu residents.

As a volunteer of Angel Heart International, a nonprofit organization dedicated to helping children with CHD in China and other developing countries, I had the opportunity to meet with Gansu families who made no more than 560 RMB ($75) per year. Lan Xiao Hua's family was one of them.

What Are Congenital Heart Defects?

Congenital heart defects are structural problems with the heart that are present at birth. Defects range in severity from simple problems, such as "holes" between chambers of the heart, to very severe malformations, such as complete absence of one or more chambers or valves. In severe defects, CHD can lead to heart failure, a condition in which the heart is unable to pump blood throughout the body. Other common results include life-threatening brain infections and the hemorrhaging of the heart.

Causes and Treatment of CHD

Researchers do not yet fully understand why CHD develop. Many scientists and philanthropic foundations highlight the role of heredity in some heart defects (American Heart Association, 2011; Bruneau 2008; Gelb & Weismann 2007; Pierpont et al. 2007). For example, an individual who has a congenital heart defect may be especially likely to have a child with a similar condition. The American Heart Association advises that pregnant women should avoid alcohol, drugs, and environmental toxins to decrease the chance that their newborns would develop congenital malformations. (American Heart Association, 2011). Unfortunately, for the majority of CHD cases, the precise cause of CHD remains unknown. Treatment ranges from procedures that use catheters to repair the defect to open-heart surgery, and, in the severest cases, heart transplants are an option.

What Is Overlooked?

While possible causal agents of CHD include drugs, chemicals, and infections during a fetus' development in the womb, or genetic and chromosomal defects apparent shortly after conception, mainstream resources for medical knowledge overlook another noteworthy possibility: socio-economic correlates. It may not be a coincidence that Gansu, China, which has a CHD incidence rate that is six times China's average, also has a poverty rate three times China's average poverty rate. Millions of rural residents in Gansu work in subsistence farming and animal husbandry, earning an average annual per capita income that's only 63% of China's average income in 2000 (Adams et al, 2008).

Extreme drought is common in Dingxi, Gansu, the home to Lan Xiao Hua, which has an annual mean precipitation of 420 mm (2006). A local saying in Gansu goes: the only time the people can shower is "at birth, marriage, and at death" because of the scarcity of water. Because water can sell at roughly 80 RMB per barrel, families struggle to provide proper nourishment for pregnant women and their growing fetuses. While it cannot be concluded that lack of precipitation is directly linked to CHD, it does, however, affect the diets and nutrition of Gansu families.

Scientists suggest that some types of congenital heart defects can be related to an abnormality of an infant's chromosomes (5% to 6% of CHD cases), single gene defects (3% to 5% of CHD cases), or "environmental factors" (2% of CHD cases). But in 85% to 90% of CHD cases, there is no identifiable causal agent of CHD. In one study, for example, maternal exposure to poisonous chemicals, negative life events, and antibiotic medicines during pregnancy were key environmental risk factors that contributed to CHD. The researchers also suggested that the frequent consumption of meat, eggs, beans and milk during pregnancy was a protective factor for CHD (Gao, Zhao & Li, 2005).

> *Today, the outlook for a child with a congenital heart defect is better than ever.*

The future

Today, the outlook for a child with a congenital heart defect is better than ever. Advances in testing and treatment give most children born with heart defects the chance to grow into adulthood and the ability to live active, productive lives. However, it is also true that Lan Xiao Hua's condition was most likely not due to genetic disorder, or irresponsible consumption of drugs and alcohol on the part of her mother. Even though she was given the best her family could offer – milk and bread – she and her mother likely suffered from malnutrition.

Lan Xiao Hua's chances of a normal, adult life are much greater today than they were a decade ago, now that she has been treated for CHD. However, until recently, she was just one of many children who were not receiving treatment for CHD. The World Health Organization estimates that the number of children with CHD waiting for treatment is between 2 million and 6 million, to which 800,000 to 1.5 million new cases are added each year (Kirby, 2010).

Limited data exists that describes the relationship between socioeconomic factors and CHD susceptibility. (Bartlett et al, 2004). Studies published on all the congenital anomalies (CAs) have either indicated no clear socioeconomic or psychosocial correlates of CHD or a higher prevalence of CAs among children born to lower social class mothers. (Knox et al, 1991; Olsen et al, 2003; Stone et al, 1989). More research is urgently needed to examine psychosocial and socioeconomic correlates of CHD incidence.

Beyond the Numbers: The Best Model of Care?

No single global health care delivery model can be generalized to the hundreds of thousands of medical causes and charities that currently exist. Many organizations, in fact, successfully work together with consultants and corporate philanthropists to determine cost-efficient ways of impacting a community. This is where we see terms such as "efficiency," "business-model, " and "results-based philanthropy" and we are made aware of how "x" many of people were helped by a "y" amount in donations. The non-profit organizational culture largely dedicated to assisting the greatest number of people, with the least amount of money and resources.

Yet an "outcomes-based" approach to analyzing medical philanthropies is deceptively simple, even as more nonprofits are drawn to a "business-model" in bringing efficiency to charity and maximizing the number of patients reached using the least amount of funds. For example, a noteworthy association of nonprofits and individuals called Little Red Scarf seeks to reach every child suffering from CHD in Gansu. However, in the case of Angel Heart International, for instance, success is not defined by the number of children cured of congenital heart defects. Instead, we aim to build a strong communication and education platform that is focused on providing family visits, effective physician-patient communication, and educational seminars for CHD patients and their family members.

How would we measure "performance output" in the case of Lan Xiao Hua? Lan Xiao Hua's sister wrote to Angel Heart International expressing that the pivotal moment in her life was not her sister's surgery but the many times volunteers "would always drop by to check up on my sister and the rest of [them], each time loaded with goodies and treats." How do we measure number-based results without taking into account the emotional support volunteers can bring before, during, and after the CHD surgery process? These are the volunteers who make day-long trips to make a single house call and are at the patient's bedside every step of the way. How do we measure the phone calls and road-trips, three years later, that are still made to visit and stay in contact with the families of every child who has worked with Angel Heart International?

We shouldn't shy away from questions of global health delivery in underdeveloped communities. For some, it will be about the numbers, the number cured of a life-threatening illness, and about managing demand, following efficiency, reducing costs, and increasing viability. Fundraising is an effective and popular approach for children, college students, and adults to become involved in a global health issue. Certainly, numbers demonstrate whether charities are accountable and financially healthy organizations. These large charities have admirable and impressive goals; their inspiring human success stories testify to the efficacy of the results-based approach. Little Red Scarf, for example, has sponsored more than 400 separate surgical operations since 2007. Organizations such as Little Red Scarf seek to provide medical care to various communities, numbering in hundreds and thousands treated per year. Some of the most ambitious organizations even seek to eliminate entire medical illnesses from certain communities.

Since its inception, Angel Heart International has expanded services to schedule medical aid for a mere 15 children in a year. Yet, we could never capture in numbers the joy that these children receive when they are finally able to attend school again, receive their first pencil box, and make friends with our volunteers. Both models, result-based care (like Little Red Scarf) and the more personal, process-based care style (in the case of Angel Heart International) are necessary. They are necessary not only for ensuring access to essential medical services, but also to allow for broader systems of social welfare capable of addressing the social determinants of health. Because every disease has a biological and more human-rooted story, solutions to each disease need to be rooted in the biomedical *and* social, humanistic sphere.

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