

Clendening Summer Fellows, 2012 Directory		
Name	Title	Pages
Abeykoon, Jithma	Insights into Ayrvedic Medicine in Sri Lanka	2 - 11
Whitney Clearwater	An Educational Intervention for Mothers and Babies in Tema, Ghana	12 - 17
Georgina Green	Caring for Bhutanese Patients in Kansas City	18 - 24
Miranda Greiner	Healthcare Providers' Perspectives on Diabetes Mellitus in Rural Guatemala	25 - 39
Brady Lonergan	Healthcare and the Role of the Orthodox Church in Byzantium	40 - 51
Rachel Myers	Jewish Genetic Screening	52 - 60
Cecilia Scrafford	Palliative Care and Hospice Medicine	61 - 66
Greg Stroh	Attitudes of Healthcare Professionals and the Public toward Early Transplantation in Patients with Acute Alcoholic Hepatitis	67 - 72
Paul Teran	Exploration of Diagnosis, Treatment, and Prevention of Child Abuse and Neglect	73 - 78
Christina Tippy	Primary Care in Tanzania	79 - 84

An Insight to Ayurvedic Medicine

Introduction

Ayurvedic medicine is the traditional way of cure practiced in the South East Asian region and has a history of a few thousand years. This medical practice has its own unique methods and values. Although Allopathic medical approach is dominant in Sri Lanka, Ayurvedic medicine is also practiced widely in society and has successfully maintained its historical social recognition. In Sri Lanka, people believe that herbal medicine can cure majority of their sicknesses. The main objective of this project is to collect specific data systematically, to identify and understand the values and beliefs in Ayurvedic medicine and its approach in treating and curing three specific diseases that are considered to have successful treatment methods. Three diseases are: Hypertension, Hyperlipidemia and Diabetes Mellitus. The main involvement of this project is scientific fact finding through analysis of data, collected through available literature, observations and interviewing techniques. The project focuses on two main frames. First is to explore treatment methods, medications, pharmacological values and second, to holistically investigate values and beliefs contributed to the claimed success of Ayurvedic medicine. Though there are some research papers published on plural approach and existence of Ayurvedic medicine in Sri Lanka, it is almost impossible to access any published literature or findings of research conducted on the treatment methods for these three diseases. This project focuses on these three diseases because, my initial investigation through discussing with the Commissioner of Western Province, Ministry of Indigenous Medicine, Sri Lanka, Dr. Nimal Karunasiri, confirmed that the Ayurvedic hospitals are treating these three diseases successfully and hence have managed to win popularity. I will gear this project to collect the information on these diseases, and collect information on values and beliefs thus focusing the project in the above two frames.

Background

My roots were in Sri Lanka until I reached 18 years. Ayurvedic medical strategy always fascinated me. The belief in the society regarding the curable power of Ayurvedic medicine made me enthusiastic and I developed a desire to investigate the basis of this medical approach. In my childhood, my grandmother used to relate stories about this subject as her uncle had been an Ayurvedic doctor. She used to tell me about leaches, and traditional herbs used to cure diseases such as boils or blood poisoning, arthritis and vascular problems. Further, in her house there had been Ayurvedic literature on ola leaf manuscripts which elaborately explained the methods for treating diseases. She considered those as very precious because they were family inherited and some being secrets. Further, her uncle had been respected and honored by the villagers because of his medical ethics and values. Ayurvedic medical service was delivered regardless of any monetary benefits.

This childhood environment made me realize that Ayurvedic medicine possessed a unique curing

power together with its own values and beliefs in delivering medical care. It is also evident that the collectivistic cultural qualities in Sri Lankan society have laid the foundation in deriving these ethics and qualities associated with this medical approach. There were incidents that I have heard about curing diseases where Allopathic medicine had failed to cure. Initially, I thought these as just beliefs lacking much scientific validity, but this school of thoughts was changed through my own experience.

In my childhood, when allergic and asthmatic conditions worsened, my parents used to take me to Ayurvedic doctors because, for these types of diseases people preferred natural herbs to western medicine. Those doctors always issued syrup made out of many herbs from their own dispensaries which gave me relief. Also, there was a time my father was suffering from a chronic pain in his ankle for about 3 years. Initially, he got Allopathic medications but it failed to cure the illness. Then he consulted an Ayurvedic doctor. I was with him when he went to this doctor's clinic which was his residence, an average house with herbs and ointment, different sizes of bottles, packed on cabinets. The doctor inquired about the history and examined the ankle by using palpation and percussion methods. After a while he sternly uttered that he could cure the sickness completely. Then he gave an ointment to apply daily at night for three weeks and advised to keep the affected area warm. That medicine cured his sickness completely. There are incidents where Ayurvedic medicine competently corrected dislocations and unhealed fractures. It claims that it can remove eye cataract without surgery. There are many incidents where Ayurvedic medicine cured strokes. These incidents gave me the insight to the strength and power of the curing methods and techniques of Ayurvedic medicine and I was motivated to investigate the value of those which might add benefit to Allopathic medical sciences as well.

There are some researches, conducted by university students, available and accessible through the web. Ediriweera et.al found that Hemiplegis is successfully cured by Ayurvedic Medicine⁴. Weerasinghe et.al states Ayurvedic medicine is popular on treating snake bites, paralysis and fractures⁷. Mano et.al tests with mice found that the herbs used in treating diabetes can reduce the blood sugar levels⁵. However, the well claimed treating methods on above mentioned three sicknesses are not explicitly researched or published.

Taking these facts into consideration, I was determined to explore further and it was my desire to investigate any valuable medicines, methods, values and beliefs which are practiced in this system to treat diseases. I feel I have the required knowledge to explore the scientific aspect of Ayurvedic medicine in treating and curing the diseases mentioned and now it is the opportune time for me to convert my desire in to practice.

Project explanation

Before proceeding to actual project explanation, I would like to shed some light on the benefits

and the potential that this project can carry to Sri Lanka and to the USA as well. Through literature reviews I have found some facts on Ayurvedic and Allopathic medicine prevailing in Sri Lanka, because those as institutions are linked to the social, economic and political structure of the society¹. Dr. Diyanath Samarasinghe, a profound psychiatrist, being a critique to the paper published by Judith and Themothy², states that health planners in under developed countries are often faced with the difficult problem of what role they should assign to traditional therapists. Further, the government wants to decide whether or not Ayurvedic doctors be used to meet the severe shortfall of Allopathic medical doctors in primary care³. Some scientific findings on the methods and success of treatments could help in this health planning decision making process. Further, raising the awareness about these treating strategies and relevant medications with a scientific background can contribute positively to Allopathic medicine. With this potential, now I will proceed to explain the project.

As I have explained, I will be investigating on how Ayurvedic medicine treats the three distinct diseases: Hypertension, Hyperlipidemia and Diabetes Mellitus and the values and beliefs associated with the system. I would like to divide this project into two main focuses. The first is to identify the treatment processes and the second to analyze and understand the overall values and beliefs of Ayurvedic medical practice.

I wish to collect data through literature reviews, interviews and observations from three different reputable sources. First source is medical practitioners and patients in Ayurvedic hospitals and clinics. There are Ayurvedic licensed medical doctors practicing in different parts of the country. I will be choosing two reputable Ayurvedic doctors to obtain information. In Ayurvedic medicine the treatment strategies, methods and equipment used might vary from one practitioner to another. Due to this heterogeneity interviewees need to be selected to represent the entire population. I will be selecting two doctors from different parts of the country. The second source will be from the lecturers in the College of Indigenous Medicine (CIM) established under the Institute of Indigenous Medicine of Sri Lanka (IIMSL). There are three CIMs in Sri Lanka and I will be choosing the one in Colombo at Nawala, Reajagiriya. The third source is from researchers in Bandaranayake Ayurveda Research Institute (BARI) of the IIMSL, located in the suburbs of Colombo. The contact details of these institutes and doctors are given in Annex 1. I have contacted the director of the college of indigenous medicine, Dr. R.A Jayasinghe and he has given me the assurance and confirmation of the availability of lecturers whom I can interview and library sources which I can utilize to obtain data for my project. Further I have obtained the permission from the Ministry of Indigenous Medicine, Sri Lanka to carry out this project and this permission will grant me the access to lecturers and library sources in CIM and to researchers in BARI to obtain data.

This multi-source data collection will enable me to gather a conclusive dataset on the two focuses of my project. The purpose of obtaining information from many sources is to be assured that my

data is reliable and valid. The findings of the first focus of the project will be systematically documented. This documentation is detailed in Annex 2. Under the second focus I will investigate the beliefs and values in Ayurvedic medicine that contribute to the success of curing the diseases. The data for this section will be collected by interviewing the two Ayurvedic medical practitioners and patients in the hospital where they practice. The contact information of the two Ayurvedic medical practitioners and the address of the hospital are mentioned in Annex 1. The interviews will be conducted through structured conversations in a casual manner to avoid difficulties and stress to the interviewee and will be conducted using a structured guideline to obtain answers to the specific questions on values and beliefs given in Annex 3. By analyzing the answers to these questions, I will be able to obtain information on beliefs and values of Ayurvedic medicine in a holistic manner.

Detailed time line of the project is given in Annex 4.

Methods

This project will be conducted through three main methods to gather data. They are literature reviews, use of interviewing techniques and visual observation. Given the fact finding nature of the project, I will not involve in sophisticated statistical analysis. Literature review will be done through National Ayurvedic and Allopathic medical libraries in Sri Lanka. This review will be focused to the research findings and published articles relevant to the three diseases and data available on pharmacological values of the herbs used in treatments.

To obtain data on these three pathological conditions and on values and beliefs, visual observations will be carried out by shadowing the two Ayurvedic medical practitioners in their clinics. I will also be interviewing lecturers who conduct classes and research personnel and the two licensed Ayurvedic medical practitioners. The access to interview the lecturers and research personnel has been obtained with the permission of Dr. Nimal Karunasiri and his permission letter will be attached in Annex 5. Further, in Annex 5, I have also attached the letters from the two medical practitioners who have agreed to guide me and support me throughout this project by facilitating shadowing events, patient interviews and sources to obtain data such as medical libraries and self-interviews.

As the above three institutions are located within a 30 miles radius from my former residence, I will be commuting to these places during weekdays and probably be spending most of my time in clinics and hospitals with interviews, shadowing, observations and reading. There is a public transport system in Sri Lanka and also an affordable private transport system which I will be making use of.

The systematic documentation of the diseases will include both categorical and numerical data. The numerical data for item #8 listed in Annex 2, will contain the number of patients seeking

treatment, their economic, social and educational background and success rates for the three diseases. Given the limited time period, retrospective data which will be obtained through BARI and CIM, will be utilized. The documentation of the rest, from items #1- #7 shown in Annex 2, will be categorical data. The documentation of values and beliefs will mostly be categorical data as this section will be framed by the questionnaire mentioned in the Annex 3.

Systematic documentation will be done by using the format mentioned in Annex 2, which will also include visuals whenever possible. One of the ways to obtain the pharmacological values of specific herbs and their ability to cure sicknesses will be interviewing the two Ayurvedic medical practitioners, profound faculty members and researchers in the CIMs and BARI respectively. Subsequently, attempts will be made to clarify details through library resources.

As I have well established roots in Sri Lanka, logistics, accommodation and contacts of mentors and institutes can be obtained without difficulty. I can get free accommodation in my former residence, located 15 miles away from CIM and BARI. I have informed the IIMSL, BARI and CIM and have obtained contact information and permission to collect data for my project. I will also access Allopathic medical libraries in Sri Lanka to gather information on Ayurvedic medical strategies as these libraries have different sections compiling literature of Ayurvedic medicine. This access will be obtained through a licensed Allopathic medical practitioner, who is my aunt, a consultant ENT surgeon in Colombo South teaching hospital in Sri Lanka.

Through my social connections in Sri Lanka, I have contacted the Ayurvedic Commissioner of Western Province, Ministry of Indigenous Medicine, Sri Lanka, Dr. Nimal Karunasiri and two other licensed Ayurvedic doctors who have given me written assurance on the support and assistance they could extend to carry out this project. Further, Dr. Nimal Karunasiri has given me permission to conduct this project in Sri Lanka and to access Ayurvedic medical literature and other resources in the BARI, and CIMs and connected hospitals. The contact information of these personnel is given in Annex 1.

Expense

The budget for this project is roughly calculated as follows.

Expense	Amount (SLRs)	Amount (\$)
Travel by Air		1700

Accommodation	5,000	50
Food	30,000	300
Transportation	10,000	100
Office ware (compute access, printing, etc)	5,000	50
Miscellaneous	20,000	200
Total		2400

Works Cited

1. Waxler-Morrison NE. "Plural Medicine in Sri Lanka: Do Ayurvedic and Western Medical Practices Differ?" 1988. Web. 27 Jan. 2012. <<http://www.ncbi.nlm.nih.gov/pubmed/2976194>>.
2. Glynn, J. R. "Factors That Influence Patients in Sri Lanka in Their Choice between Ayurvedic and Western Medicine." *British Medical Journal* 291 (1985): 470-72. <<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1416745/?page=2>>.
3. Jeyarajah R. "Factors That Influence Patients in Sri Lanka in Their Choice between Ayurvedic and Western Medicine." 28 Sept. 1985. Web. 27 Jan. 2012. <<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1416745/?page=1>>.
4. Ediriweera ER ER. "Clinical Study on the Efficacy of Chandra Kalka with Mahadalu Anupanaya in the Management of Pakshaghata (Hemiplegia)." Jan. 2011. Web. 27 Jan. 2012. <<http://www.ncbi.nlm.nih.gov/pubmed/22131754>>.
5. Mano H. "Mechanisms of Blood Glucose-lowering Effect of Aqueous Extract from Stems of Kothala Himbutu (*Salacia Reticulata*) in the Mouse." Jan. 2009. Web. 27 Jan. 2012. <<http://www.ncbi.nlm.nih.gov/pubmed/19028559>>.
6. Nordstrom CR. "Exploring Pluralism--the Many Faces of Ayurveda." 1988. Web. 27 Jan. 2012. <<http://www.ncbi.nlm.nih.gov/pubmed/3227356>>.
7. Weerasinghe MC. "Paradox in Treatment Seeking: An Experience from Rural Sri Lanka." Mar. 2011. Web. 27 Jan. 2012. <<http://www.ncbi.nlm.nih.gov/pubmed/20935237>>.

The contacts of mentors and other respective sources

Commissioner of western province, Ministry of Indigenous Medicine, Sri Lanka

Name- Dr. Nimal Karunasiri,

Designation - Commissioner of Western Province, Ministry of Indigenous Medicine Sri Lanka

Address- Ministry of Indigenous Medicine, Sri Lanka

National Ayurvedic Medical College and hospitals

Name- Dr. R.A. Jayasinghe

Designation - Director of indigenous medicine - Rajagiriya

Address- National Ayurvedic Medical College, Rajagiriya, Sri Lanka

National Ayurvedic research center

Name- K.D.S. Ranaweera

Designation- Professor

Address- Institute Bandaranayaka Memorial Research Institute, Navinna, Sri Lanka

Licensed Ayurvedic medical practitioners

Name- Dr. H.A.M Sriyani

Designation- Doctor of Ayurvedic Medicine

Institute- Ayurvedic Hospital

Address- Minipe Pradeshiya Saba (provincial level hospital), Hasalaka, Sri Lanka

Name- Dr. H.P Jayadasa

Designation- Doctor of Ayurvedic Medicine

Institute- Gampaha Ayurvedic dispensary

Address- 40. A, Rahula Road, Katubadda, Moratuwa, Sri Lanka

Address of the hospital where the shadowing of doctors and interviewing patients will take place-

Minipe Pradeshiya Saba (provincial level hospital)

Hasalaka

Sri Lanka

Licensed Allopathic medical practitioner

Name: Dr. Malkanthi Jayasinghe

Designation- Doctor of Allopathic medicine, Consultant ENT surgeon

Institute- Kalubowila Government Hospital

Address- ENT Department, Kalubowila Government Hospital, Sri Lanka

Annex - 2

Systematic documentation of the first focus of the project will be structured in the following format:

1. *Disease of interest*- This will be one of the three diseases
2. *Investigation and diagnosis*- Pertaining to Ayurvedic medicine, the clinical symptoms of these diseases. The methods used to investigate and diagnose the pathological conditions. This could be via physical examinations, laboratory tests and any other methods used by Ayurvedic doctors.
3. *The approach*- What is the plan of treatment after the diagnosis. Example: Herbal drugs, therapy such as massage and heat, etc.
4. *Treatment strategies*- Treatments given based on gender and age via different routes to the body such as oral, through skin contact, etc. and therapy
5. *Medications used*- This will include a list of all the ingredients used to prepare herbal medications.
6. *Pharmacological value of the medications*- This will include the scientific and pharmacological value of using the above mentioned ingredients such as different herbs, in preparing medications.

7. *Theoretical basis of using the medications*- This will include the rationale behind the usage of each medication for specific diseases.
8. *Expected time period of healing and success rate*- Report of the time period and the success rate of treatment.

Annex - 3

The questionnaire to obtain data on values and beliefs of Ayurvedic medicine, i.e. the second focus of the project

Beliefs

1. Does the Ayurvedic medical practice rely on Astrological beliefs?
2. If yes, how one could tie those beliefs with treatments for specific diseases?
3. What other social or cultural beliefs does the Ayurvedic medical practice have?
4. If known, how these beliefs have evolved in this field of medicine?
5. Are there any specific cultural or social beliefs associated with specific diseases and their treatments?
6. If yes, what are those and why does Ayurvedic medicine believe that these beliefs are important in the process of treatment for specific diseases?

Values

1. What are the core values of Ayurvedic medical practice? For example, in Allopathic medical practice one of the core values is “do no harm”. Likewise, what are the values in Ayurvedic medical practice?
2. Are there any strategies or methods that Ayurvedic medicine uses to deliver sensitive information to patients?
3. How does Ayurvedic medicine value patient’s confidentiality?
4. How does Ayurvedic medicine approach a terminally ill end-stage patient with respect to values and ethics?
5. How does Ayurvedic medicine value the patient-physician relationship? Are there any physician paternalism expressed in this relationship?

Annex - 4

Time line of the project

May 12 - Travel to Sri Lanka.

May 15th - 18th - Introducing the project goals and targets to Ayurvedic medical practitioners, Ayurvedic medical school and to the Ayurvedic research center and completing the initial requirements to access Ayurvedic medical literature. Setting appointments with Ayurvedic medical school, national Ayurvedic research center and Ayurvedic medical practitioners

Investigation on hyperlipidemia and hypertension

May 21th - May 23th - Visit Ayurvedic medical school for interviews, investigation and data collection.

May 26nd - May 28rd - Visit national Ayurvedic research center for interviews and obtain data

May 28th - May 30th - Visit Ayurvedic medical practitioners for interviews and obtain data

May 31st - June 4nd - Visit national libraries for collecting literature

Investigation on diabetes mellitus

June 5th - June 7th - Visit Ayurvedic medical school for interviews, investigation and data collection

June 8th - June 12th - Visit national Ayurvedic research center for interviews and obtain data

June 13th - June 15th - Visit Ayurvedic medical practitioners for interviews and obtain data

June 18th - June 19th - Visit national libraries for collecting literature

Investigating and obtaining information regarding values and beliefs of Ayurvedic medicine

June 20th - June 22nd - Visit Ayurvedic medical school for interviews, investigation and data collection

June 25th - June 27th - Visit national Ayurvedic research center for interviews and obtain data

June 28th - July 2nd - Visit Ayurvedic medical practitioners and patients for interviews and obtain data

July 3rd - July 5th - Visit national libraries for collecting literature

Inclusion of gathered data to a thesis and summarize the project in a conclusive manner

July 8th - July 12th - Documentation of the obtained data and writing a paper

July 12th - July 17th - Making a power point presentation

July 17th - July 20th - Final wrap-ups

Annex - 5

Below are the letter of permission to carry out this project in Sri Lanka and letters from the two medical practitioners who have agreed to guide me and help me throughout this project.

Clendening Summer Fellowship
Department of History and Philosophy of Medicine
University of Kansas School of Medicine
2012

Whitney Clearwater
School of Medicine
Class of 2015

Targeting a captive audience:
an educational intervention for moms and babies in Tema, Ghana

Introduction

The United Nations identified eight areas of dramatic need threatening the lives of our global community in their Millennium Development Goals (MDGs). The fourth MDG is to reduce child mortality, identified in part because annually nine million children die before reaching their fifth birthday (United Nations, 2010). The fifth MDG is to improve maternal mortality. Each year 350,000 women die from childbirth or complications of pregnancy (UN, 2010). Further, sub-Saharan Africa has a disproportionate burden of poor health outcomes and is a major focus of interventions to reach the MDGs.

This disparity in health outcomes is exemplified in Ghana, a sub-Saharan African country, where maternal and child mortality is a significant problem. For instance, in Ghana the lifetime risk of maternal death is 1 in 66 compared to the United States which is 1 in 2100 (United Nations Children's Fund, 2010). Additionally, the under five mortality rate in Ghana is 69 per 1000 live births compared to 8 per 1000 live births in the US (UNICEF, 2010).

In response the poor health outcomes, Ghana initiated a national health insurance scheme (NHIS) in 2003. The NHIS successfully increased the likelihood of women receiving prenatal care, delivering at hospitals with trained health professions present, and decreased birth complications for the population of women using this service (Mensah et al., 2010). However, underutilization undermines the success of the NHIS. For example, only 57% of Ghanaians deliver their babies in the presence of a skilled attendant compared to 99% in the US (UNICEF, 2010). Additionally, among children under the age of five only 45% with diarrhea receive oral rehydration and 51% with suspected pneumonia are taken to an appropriate healthcare provider (UNICEF, 2010).

The physicians and other providers at the Women's Ward at Tema General Hospital (TGH) in Tema, Ghana are committed to addressing the maternal and child health crisis, regardless of their

limited staff and resources. Due to their limited staff, ante-natal patients often have long wait times at the hospital before they are seen by a health professional.

For my Clendening Fellowship, I am proposing to provide my skills in data analysis and as a health educator to work toward prevention services that might ease TGH's burden. I am proposing to target the captive audience of ante-natal patients and provide a pre- and post-natal education intervention that will serve to address delays in accessing care.

Background

Dr. Montello addressed a group of first year medical students interested in the Clendening Fellowship and challenged us to think of what we wanted to do with this one life we have. If I could do only one thing in this life it would be to work for women's rights in healthcare. I arrived at this mission after witnessing dramatic disparities in women's rights regarding access to healthcare both internationally and locally.

In the summer of 2007, in Tanzania while working with a local physician and educating high school students and peer support groups on HIV/AIDS I gained the passion for my life's ambition. During this experience I was abruptly shown the inequalities in healthcare access and education. Unfortunately, these inequalities often have a greater impact on women. In many societies women's status is inferior to men's. This prevents access to education, resources, and healthcare. However, raising the health status of women has a greater effect on the health outcomes of a community. Women often fill the role of caretakers for the community. Through this experience I identified a need to help underserved women but also an opportunity to sustainably improve health outcomes of a community.

In order to gain a broader understanding of the determinants for inequalities in healthcare I pursued a Masters in Public Health. I earned a degree in biostatistics and epidemiology so that I may be able to analyze the determinants of health and foster support for effective means to improving lives. During my masters, I took every opportunity to reach beyond the classroom and apply the skills I learned. I attended a United Nations conference in Australia that brought together Non-Governmental Organizations working to achieve the MDGs. At this conference I saw a template for partnering with communities to identify health problems and own solutions. Additionally, I completed an internship as a Middle School Reproductive Health Educator at Planned Parenthood Los Angeles. While educating in underserved populations in Los Angeles I witnessed shocking lack of access to healthcare and education similar to what I observed in Africa. For example, one of my 7th grade students asked me if drinking milk could prevent pregnancy. I learned that working toward improving the lives of underserved women abroad can inform work with similar communities right next door.

I entered medical school with a passion and motivation to ease individual's suffering and improve health outcomes. The practical clinical tools and critical thinking gained during my training at KUMC will help me to work toward this goal. However, clinical care while direct and powerful is only a part of sustainably improving health outcomes. In order to continue my experience in community service I joined the boards of the Community Leadership Track founded by Dr. Allen Greiner and Dr. Joshua Freeman, Health Professionals for Human Rights, and am active at JayDoc.

If approved, my experience in Ghana will capitalize and strengthen my skills learned from previous experience but also help me to realize my passion and achieve my goals. My hope is not only to provide a service that can benefit the patients at TGH but also translate these skills in building culturally appropriate and need based education curriculum for underserved women locally.

Description

The goal of my project is to provide a needed health service to the Women's Ward of Tema General Hospital. I have identified three objectives necessary in achieving my goal. The first objective is to develop and provide an educational intervention for ante-natal patients at TGH. Next, to determine whether the educational intervention was successful in addressing a need for the patients I will statistically evaluate changes in knowledge using a pre- and post-knowledge assessment. Finally, I will share the results of my research with the providers at TGH for use in future educational interventions and applications for funding.

The choice of an educational intervention was to address the delays in access to care in a sustainable and feasible manner. Recognized delays in access to obstetric care include the delay in recognizing warning signs and severity, physically reaching care, and the delay in accessing appropriate care once at a healthcare facility (Cham et al., 2005). I believe a needs-based and culturally appropriate education intervention will address both the delay in recognizing warning signs as well as provide prevention tools for ante-natal patients as they prepare for the birthing process and childcare.

Additionally, interventions that target education of women tend to improve outcomes for the community and therefore are a potentially sustainable approach. The World Bank states that, "girls' education yields some of the highest returns of all development investments, yielding both private and social benefits that accrue to individuals, families and society at large" (Lawson, 2008). When women become educated and go to work fertility rates decline, mother-infant mortality decreases, standard of living increases as well as life expectancy and health overall (Lawson, 2008).

Timeline:

March 1, 2012: Apply for KU Human Subjects Committee exemption.

March 11, 2012 – May 11, 2012: Shadow Dr. Gene Lee, JayDoc Women's Health Night providers, and Suzanne Ryan.

May 13, 2012 – May 18, 2012: Conduct a literature review.

May 13, 2012 – May 18, 2012: Develop an outline for the focus group to be held in Ghana with practitioners and patients.

May 19, 2012: Travel to Tema, Ghana.

May 21, 2012 – May 25, 2012: Facilitate a focus group with TGH practitioners and patients.

May 28, 2012 – June 1, 2012: Develop a 45 minute curriculum on pre-natal and post-natal care that is both needs based and culturally appropriate.

June 4, 2012 – June 8, 2012: Develop pre- and post- knowledge assessment survey.

June 11, 2012 – June 15, 2012: Sample the clarity and understanding of the pre- and post-test with a sample population of ante-natal patients.

June 18, 2012 – July 6, 2012: Conduct a minimum of three education sessions with the pre- and post-knowledge assessments.

July 9, 2012 – July 13, 2012: Analyze quantitative knowledge change using STATA software.

July 16, 2012 – July 20, 2012: Facilitate a debriefing with the providers from TGH.

July 21, 2012: Travel to Kansas City.

Methods

I will be working closely with Dr. Greiner and Dr. Kessler throughout my project. Both Dr. Greiner and Dr. Kessler assisted with formatting my project to be comprehensive and applicable to my interests and the interests of TGH. Dr. Kessler is an adjunct faculty at KUMC and has contact with Dr. Deganus the physician at TGH.

To develop a curriculum that is based on the needs of a high risk population and to obtain information about standard of care protocols, emergency procedures, and education topics and strategies I will shadow and discuss suggested educational topics with local providers. The providers that have agreed to assist me information gathering include: Dr. Gene Lee, OB/GYN physician at KUMED, JayDoc OB/GYN's at their Women's Health Night, and Suzanne Ryan, a local midwife. A literature review of information on education topics and strategies as well as pre-existing education material from NGOs operating in Ghana will also help inform my educational curriculum. Finally, I will conduct a focus group with physicians and patients at TGH to gather qualitative data on cultural and geographic determinants involved in pre- and post-natal warning signs, best practices, and needs assessment regarding reproductive health. The template for the education intervention will include both pre-natal and post-natal care information. The pre-natal portion will include a birth plan, prevention strategies, warning signs of imminent labor and potential complications for the baby, and at home tools in case hospital

delivery is not an option. The post-natal portion will include prevention of infection, management of breastfeeding and nutrition, warning signs for the baby, and contraceptive use. The skills I developed as a reproductive health educator in both Tanzania and Los Angeles will aid in my ability to effectively deliver this curriculum.

In order to evaluate the effectiveness of the educational intervention I will conduct a pre- and post-knowledge assessment. I will obtain KU Human Subject's Committee exemption because there is less than minimal risk for an anonymous survey. Pre- and post-knowledge assessments will be administered to the sample of patients participating in my educational intervention. The post-assessment will additionally include a satisfaction component in order to improve subsequent interventions that TGH might incorporate. To increase the power of associations between changes in knowledge I will conduct a minimum of three educational interventions with pre- and post-knowledge assessments. I will analyze the data using STATA, a bio-statistical computer program in which I have experience.

Finally, I will debrief the providers at TGH about my research outcomes so that they may utilize the information for future education interventions or applications for funding. Specifically, I will elaborate on topics where patients scored lowest as well as aspects from the intervention that were enjoyed most.

Contacts

Allen Greiner, MD, MPH
Professor and Associate Chair for Research
University of Kansas School of Medicine

Sarah Kessler, PhD, MPH
Assistant Adjunct Professor
University of Kansas School of Medicine

Dr. Deganus
Physician at Tema General Hospital's Women's Ward, Ghana

Gene Lee, MD
Obstetrics and Gynecology
University of Kansas Physicians
Medical Office Building

Suzanne Ryan, MSN, CNM, WHCNP
Suzanne Ryan & Associates Midwives

(877) 551-0001

See appendix for correspondence with contacts and mentors.

Budget (see appendix)

Category	Estimated Cost	Subtotal
Travel (airfare)	\$1801.00	\$1801.00
Room and Board		
Food	\$10/day x 65 days	\$650.00
Lodging	\$17.50/day x 65 days	\$1137.50
Laundry Facilities		\$50
Incidentals		
Transportation		\$50
Printing costs (surveys)		\$50
Grand Total		\$3738.50

If accepted for the Clendening Fellowship, I understand that I will be personally responsible for expenses that exceed the funds provided by the scholarship.

Bibliography

Amamosh, B.O., Moussa, K.M., Stafstrom, M., Musinguzi, G. (2011). Distribution of causes of maternal mortality among different socio-demographic groups in Ghana. *BioMed Central Public Health*. 11: 159.

Cham, M., Sundby, J., Vangen, S. (2005). Maternal mortality in rural Gambia, a qualitative study on access to emergency obstetric care. *Reproductive Health*. 2-3.

Gumanga, S., Kobila D., Gandau, B., Munkaila, A., Malechi, H., Kyei-Agoagye K. (2011). Trends in maternal mortality in Tamale Teaching Hospital, Ghana. *Ghana Medical Journal*. 45(3): 105-10.

Lawson, S. (2008). Women hold up half the sky. *Global Economics Paper No. 164*. Goldman Sachs.

Mensah, J., Oppong, J.R., Schmidt, C.M. (2010). Ghana's National Health Insurance Scheme in the context of health MDGs: an empirical evaluation using propensity score matching. *Health Economics*. 19: 95-106.

United Nations. (2010). *Millennium Development Goal 4: reduce child mortality – fact sheet*. Retrieved from http://www.un.org/millenniumgoals/pdf/MDG_FS_4_EN.pdf

United Nations. (2010). *Millennium Development Goal 5: improve maternal health – fact sheet*. Retrieved from http://www.un.org/millenniumgoals/pdf/MDG_FS_5_EN_new.pdf

United Nations Children's Fund. (2010). *At a glance-Ghana statistics*. Retrieved from http://www.unicef.org/infobycountry/ghana_statistics.html

United Nations Children's Fund. (2010). *At a glance-United States of America statistics*. Retrieved from http://www.unicef.org/infobycountry/usa_statistics.html

Clendening Summer Fellowship Application 2012

Georgina Green

March 21, 2012

Developing Cross-Cultural Competency to Serve the Healthcare Needs of the Bhutanese Refugee Population in Kansas City, Kansas

Introduction:

The primary goal of this project is to gain skills necessary to be a more effective and responsive health care provider for Bhutanese refugees. Lessons learned then will be shared with other healthcare practitioners.

Specific objectives of this project include the following:

1. Develop Nepali language skills.
2. Volunteer with the local Bhutanese community.
3. Shadow a physician in a clinical setting with Bhutanese patients.
4. Participate in a mental health project designed to assist the Bhutanese community in Kansas.
5. Learn about Bhutanese refugee experiences during their expulsion from Bhutan, during their time in refugee camps in Nepal, and as they establish their lives in Kansas City, Kansas.
6. Share lessons about cultural competency with other healthcare practitioners.

Background:

In August of 2011, three weeks after my first day of medical school, I met a Bhutanese woman at the student-run Jaydoc free clinic. We spoke through a translator for over an hour, however I left the clinic that night feeling bewildered by a communication barrier that seemed greater than just a language gap. We met the patient's immediate need that night; nevertheless, I felt as if I had asked the wrong questions and that I did not properly understand how she expressed thoughts about her body, her pain, or her emotions. Although I was listening intently and was engaged, there was an obvious gap in my own cultural competency. I did not know about Bhutanese culture, spiritual beliefs, or traditional medicine, and I knew nothing about the Bhutanese refugee community in Kansas City. Soon after the Jaydoc experience, I was shadowing in labor and delivery at KUMC and witnessed a similar patient interaction. Two kind, compassionate doctors were using a telephone translation service to talk to a new mother. Yet again, I left the room with a lingering feeling that there had been barriers to communication that went beyond language.

Through these patient interactions, I felt that I needed to learn more about the Bhutanese community and their experiences in order to be an effective healthcare provider. This will be important when I become a physician, but it is also relevant now as a student while volunteering at the JayDoc free clinic, working with patients in the hospital at KUMC, and interacting with parents at the proposed school-based health clinic sites in Kansas City, Kansas.

In October of 2011, not long after meeting the Bhutanese women, I attended the INMED International Institute of Medicine Conference in Kansas City, Kansas, and met Dr. Joseph LeMaster when he gave a presentation about healthcare for the Bhutanese community in Kansas. Dr. LeMaster, my mentor for the Clendening fellowship, worked in Nepal for over two decades, is fluent in Nepalese, and is an advocate for the Bhutanese community in Kansas. With Dr. LeMaster's guidance, I developed a summer project that will enable me to improve my cultural competency and then share the lessons learned.

In the early 1990s the Bhutanese government engaged in systematic "ethnic cleansing" of approximately one sixth of its population, a minority group of Bhutanese who were Hindu and spoke Nepalese. Over 100,000 people fled to Nepal and lived in temporary refugee camps under the protection of the Office of the United Nations High Commissioner for Refugees (UNHCR).

After nearly twenty years of living in the camps, hope of repatriating back to Bhutan dwindled. In 2007, refugees began to permanently resettle in third countries, such as Australia, Sweden etc., and the United States agreed to permanently resettle 60,000 of the 100,000 Bhutanese. In recent years approximately 400 Bhutanese refugees, approximately seventy-five families, have moved to Kansas City, Kansas, area.

Cultural competency can be defined as awareness, attitude, knowledge, and skills: “(a) Awareness of one's own cultural worldview, (b) Attitude towards cultural differences, (c) Knowledge of different cultural practices and worldviews, and (d) Cross-cultural skills [such as language]. Developing cultural competence results in an ability to understand, communicate with, and effectively interact with people across cultures” (Martin & Vaughn).

Ultimately, the litmus test for this project's success will be the quality of my interactions with Bhutanese patients following this summer project. My hope is that the invisible veil that I felt between the patients and myself will be lifted.

Project Description and Methods:

1. Develop Nepali language skills:

Textbooks and other media will be used to learn written and spoken Nepali. By the beginning of June I will have acquired basic language skills. I will then work with a conversational partner, preferably someone who can improve her English skills as I benefit from her help in learning Nepali. (There may be other refugee communities that speak Nepali, in which case the language skills will also be helpful.)

2. Volunteer with the local Bhutanese community:

I will volunteer at a Bhutanese community garden throughout the summer. It will allow to meet Bhutanese people socially and allow my family to be involved in the project, but more importantly, it will provide the opportunity to be of service.

3. Shadow a physician in a clinical setting with Bhutanese patients:

Dr. LeMaster sees Bhutanese patients in the family practice clinic on Wednesday afternoons, and I will be able to shadow him. Though patient interactions are in Nepalese, I will be able to observe nonverbal communication and then ask questions following the patient encounters.

4. Participate in a mental health project that has been developed to assist the Bhutanese community in Kansas:

Dr. LeMaster recently initiated a mental health project housed at the Wyandot Mental Health Center called, “Chautari: Increasing Access to Mental Healthcare and Community Support for Bhutanese Refugees.” The Bhutanese are one of Kansas’ ethnic groups at highest risk of suicide and psychological distress. This is in part related to the torture, rape and other experience during the “ethnic cleansing” and forced expulsion from Bhutan. Psychological distress may also be related to experiences from the refugee camps in Nepal or from the stress of adapting to life in the United States. The goal of the Chautari project is to provide culturally appropriate and effective mental health care for the Bhutanese community in Kansas.

Through the Chautari project, I will be able to participate in data collection and analysis of the focus groups and interviews to assess the progress of the Chautari project. Prior to medical school, my main professional interest focused on refugee protection and resettlement, and I have some experience with qualitative data collection and analysis. My Master’s thesis was, “A Needs Assessment of Somali Refugees in London, England, in 2000 and the Role of Community Associations in Meeting Those Needs.” That summer I traveled to seven Somali community associations throughout London and spoke to Somalis about their resettlement experiences. In 2000 I participated in a needs assessment for the Georgia Refugee Resettlement Program in which I transcribed interviews, analyzed data, and contributed to the final report called, “Refugee Needs Assessment for State of Georgia Department of Humans Services Section, Refugee Resettlement Program.”

In addition, in the summer of 2003 I completed an internship with the International Rescue Committee’s Protection SURGE Capacity Project and United Nations Liaison Office in Geneva, Switzerland. The SURGE project provided short-term refugee protection workers throughout the world in collaboration with the Office of the United Nations High Commissioner for Refugees.

5. Learn about Bhutanese refugee experiences during their expulsion from Bhutan, during their time in refugee camps in Nepal, and as they establish their lives in Kansas City, Kansas:

Much has been written about the experiences of the Bhutanese refugees. Articles from the 1990's document treatment of the Bhutanese during expulsion from the country, including accounts from Amnesty International and Human Rights Watch. During the two decades of camp life in Nepal, articles were written about mental and physical health in camps. More recently articles have been written about Bhutanese resettlement experiences in various countries. My intention is to read broadly and learn as much as possible about the religion, culture, and experiences of this population.

6. Develop means for sharing lessons about cultural competency with other healthcare practitioners.

My hope is that the experiences and knowledge gained from this summer will provide me with the tools that I need to serve Bhutanese people that I meet. The goal is not to stereotype patients as “Bhutanese” or “refugee” and see them through one lens; rather, there are specific things that it would be helpful to know when working with someone who is from this background. Empathy and communication both come more easily when there is a basic understanding, and with deeper knowledge, one is perhaps more able to treat the patient as a whole person rather than “other” or “foreign.” The lessons that I learn about cross-cultural competency will be shared in two ways. First, I will develop a brief course for healthcare practitioners who want to learn more about the Bhutanese and how one can provide more effective healthcare for them. Second, I will write an article that shares the same information in a different format.

Timeline:

April 1-

- Begin learning Nepali language
- Attend Bhutanese community meeting
- Begin attending meetings of grad students in Family Medicine (see what they are working on, what resources are available, etc.)

May 15th-

- Begin weekly meetings with Nepali language conversational partner.
- Begin volunteering in the community garden.
- Begin shadowing community health worker on home visits.
- Begin shadowing Dr. LeMaster in clinic.
- Meet with person at INMED regarding cross-cultural competence training.
- Approach office for continuing education about requirements for certifying a course.

June 1-July 30

- Participate in round tables regarding mental health project. Transcribe interviews and contribute to analysis.
- Complete article and submit for publication
- Complete Bhutanese cultural competency course, submit for approval, and schedule at least one presentation.

There are many questions that arise that could be explored at the level of doctoral theses, but are not within the scope of this project. This summer project will not delve into many of the larger questions about the experiences of Bhutanese refugees. Nevertheless, as time permits, I will research those topics to broaden my understanding of the experiences of Bhutanese refugees. I am curious about traditional Bhutanese medicine and the kind of health care that was available in the camps. I want to know if women are having different experiences from men as they adapt to life in the US, and how the children are faring in the local schools. I am also curious about gender-based violence that women may have experienced during the expulsion from Bhutan and in the camps. Through this project I hope to learn more about the realities of people's experiences, their coping mechanisms, the current stresses that they face, and whether or not mental health programs are able to meet those needs.

Many parts of the refugee resettlement experience have a similar refrain, no matter what country a person moves from. While one can make generalizations, it is important to realize that there are aspects of the Bhutanese experience in Kansas that are unique; the community has its own challenges and strengths that shape the resettlement experience. I hope to gain a greater

understanding by meeting people, hearing their stories, and listening to their successes and their struggles.

Budget:

Grant funding will be used for language learning materials and for travel to and from KUMC, the community garden, and Wyandot Center. The remainder of the grant will be used to supplement living expenses for the duration of the project.

Conclusion:

In conclusion, as a medical student one quickly realizes that there are many aspects of a medical education that cannot be covered in a lecture hall or an anatomy lab. The Clendening Summer Fellowship provides a rare opportunity to explore and learn in ways that are personal and transformative. In A Room of One's Own, Virginia Woolfe suggested that every woman writer needs the luxury of time, space and financial resources in order to be productive and tap her potential. Clendening provides a unique “room of one’s own” to budding physicians by providing sufficient time and resources for a student to explore, be creative, and learn in ways that will allow us to become better physicians. With the help of the fellowship, I will have the unique opportunity to learn about the Bhutanese community so that I can become a more effective and responsive health care provider for the Bhutanese patients that I meet.

Resources:

1. www.bhutanese-refugees.com
2. www.inmed.us- website of the Institute for International Medicine
3. www.kansasbhutanesecommunity.org
4. “The Pursuit of Home: The Bhutanese Refugee Situation in Kansas City”- a video of members of the Kansas Bhutanese Community talking about life in Bhutan and expulsion from their home country.
5. “Cross Cultural Competencies and Objectives,”
http://www.valdosta.edu/~karowlan/Cross-Cultural_Competencies1.htm

Health Care Providers' Perceptions on Diabetes Mellitus in Rural Guatemala

Miranda Greiner

University of Kansas School of Medicine

Clendening Fellowship Proposal

February 13th, 2012

Introduction

Diabetes is a social disease; successful management depends not only on an individual patient's decisions and behaviors, but also on his or her interactions with other people. In indigenous Maya communities of Guatemala, where diabetes is one of the most common diseases, poverty, inaccessible health care, and limited educational opportunities complicate the diagnosis and treatment of diabetes mellitus. However, social interactions with friends, family members, and a myriad of competing health care providers significantly influence patients' experiences of diabetes as well. This study will explore health care providers' knowledge, attitudes, and care approaches for diabetes in four indigenous Guatemalan villages. These results will be used to develop a set of quality improvement goals and objectives for patient management in each of the four clinical settings.

Background

Guatemala has the highest indigenous population in Central America, and second-highest in all of Latin America. Despite Guatemalan Ministry of Health (MOH) efforts, there is a great lack of health care resources for indigenous population in rural areas. Health care accessibility in these areas is vital with the growing burden of non-communicable diseases such as diabetes. Within the indigenous population, type II diabetes mellitus is driven by a prevalence of sedentary lifestyle and brought about by increased urbanization and the decline in traditional agricultural lifestyles.

The primary treatment costs and adverse effects of diabetes result in an economic burden that weighs heavily on the more impoverished, rural areas of Guatemala. The debilitating effects of this chronic illness can threaten a person's employment and thus the overall well-being of an entire family. Along with the economic burden, diabetes is a social disease. The adherence to treatment is not only dependent on the individual patient but their family and social groups. Knowledge of diabetes varies within a broad range and can be affected by cases of medical pluralism. This references the often contradictory medical advice stemming from various sources such as: pharmacists, midwives, natural healers, market vendors, nurses, family members and friends.

While volunteering with the non-profit organization Wuqu' Kawoq, I observed the effects of medical pluralism amongst diabetic patients and their treatments. For example, Maria has been a diabetic patient for the past seven years and has sought various sources for her treatment. She first entered the program with Wuqu' Kawoq after being diagnosed with diabetes in a health center. She arrived at one of the free clinics for a blood glucose test to see if her current treatment of herbal remedies was working to lower her blood sugars. With a resulting glucose level of 232 mg/dl, I counseled Maria on diabetes. Maria obtained her free medications (metformin and glyburide) that day at the clinic but did not return for six months. Upon her six month return she was still using herbal remedies prescribed by a natural healer and believed her diabetes could be cured. Maria represents a common dilemma with diabetic patients and treatment adherence.

Many patients are vulnerable to the various sources of medical advice when there are no education initiatives within their communities. These issues can be overcome by extending the availability of quality medical services and diabetes educational groups. The social implications and immediate biomedical aspects of diabetes mellitus are inseparable and there is a great need to implement these programs within the indigenous population to approach these obstacles.

This past year, I volunteered with Wuqu' Kawoq and addressed our patients' needs in diabetes education. I partnered with the Institution of Nutrition in Central America and Panama (INCAP) and APRECOR (Guatemalan Organization for Prevention of Heart Disease) to create a manual on cardiovascular disease. I completed the manual with a focus on cultural adaptations for the rural diabetic patient population. The content of the manual was based upon results from a preliminary ethnographic investigation on perceptions of diabetes among indigenous patients. The manual addresses issues such as diabetes as a chronic medical illness, causation, diet and modifications, related organ damage, and the significance of familiar and peer support. The manual served as an important tool to overcoming some of the confusing advice provided within remote rural areas.

Although ethnographic surveys were distributed among the diabetic patients, there is no data on perceptions of diabetes among the health care providers in these rural areas. Much of the medical advice and information on diabetes is stemming from various sources including midwives, natural healers, nurses, physicians, and other health care providers. There are commonly more traditional healers (midwives, natural healers) than physicians in the remote rural areas. There is a need to better understand the perceptions of these various health care providers and to encourage a culturally-sensitive method for advancing the quality of care for diabetes.

Description

To better understand health care providers' perceptions on diabetes, I will conduct qualitative surveys to explore the knowledge, attitudes, and practices of health care providers within the rural communities San Juan Comalapa, Tecpan, Santiago Sacatepéquez, and San Lucas Toliman. I will interview approximately twenty-four health care providers of various backgrounds such as natural healers, pharmacists, midwives, nurses, and physicians. I will interview six different health care providers from each community. The participants in the study will be selected through previous contacts and health care affiliates. The occupation of these health care providers will depend on the demographics of each community. For instance, the community of Tecpan is more urbanized than San Juan Comalapa and might have higher-educated health care providers such as nurses or physicians. Also due to the demographics of the indigenous communities, there are fewer physicians in these rural communities. Most physicians are located in more urbanized areas such as Guatemala City. I will predominantly interview midwives, natural healers, pharmacists, and then nurses in each community.

Many of the health promoters in these communities speak Kaqchikel Maya as their primary language and Spanish is their second language. I will determine their language preference before each interview. I am fluent in Spanish and at an intermediate level in Kaqchikel Maya. Due to the variance in Kaqchikel Maya between the communities, I will hire a Kaqchikel Maya translator when the interviewee's preference is Kaqchikel Maya. The qualitative surveys will be carried out in an informal interview setting. Each survey is written in Spanish for a translator to read because Kaqchikel Maya literacy is not common.

Guatemala presents barriers to travel often and other potential conflicts. Some of these conflicts arise due to detrimental weather (i.e. mudslides, volcanic eruptions, etc.), increased violence upon local chicken-bus travel, or other issues. This will potentially affect the study sample size.

I plan on carrying out qualitative research in Guatemala for four weeks with one week of Kaqchikel Maya lessons at the end of my stay. Most individuals in the rural villages speak Maya language as their first language and Spanish is their second language. In the more poverty-stricken communities, it is common for a person to complete only *educación básica*, or four years of schooling. Thus, many individuals in these regions depend on their primary language, and not Spanish. There are over half a million Kaqchikel Maya speakers in the Guatemalan highlands and most of the current diabetic patients speak Kaqchikel Maya. A higher level of fluency in Kaqchikel Maya is important within these smaller villages and I would like to further my studies with a native speaker. I will dedicate approximately two weeks in completing transcription of all interviews and data analysis in Kansas City where there are more resources such as computer accessibility.

Every week I will attempt to travel to a different community to see current diabetic patients with a community health worker and follow-up on their treatments. Below is a tentative schedule with a later departure to Guatemala because I will be presenting past research on diabetes at the Native American and Indigenous Studies Association (NAISA) Conference in Connecticut (this expense is not included in my budget).

March 5th - Begin IRB application with the Human Subjects Committee.

[June 3rd – June 6th] NAISA Conference in CT.

[June 9th – July 15th: Guatemala]

[July 16th – July 28th: Kansas City]

June 9th – 10th - Arrive in Antigua, Guatemala.

June 11th, Monday – Travel to Santiago, Sacatepéquez.

June 12th, Tuesday – Interview 2 Health Care Providers.

June 13th, Wednesday – Transcribe interviews.

June 14th, Thursday – Interview 2 Health Care Providers. /See patients with Guicha.

June 15th, Friday – Interview 2 Health Care Providers.

June 16th, Saturday – Schedule interviews for following weeks. /Travel to San Juan Comalapa.

June 17th, Sunday - *Rest*

June 18th, Monday – Interview 2 Health Care Providers.

June 19th, Tuesday - Transcribe interviews.

June 20th, Wednesday - Interview 2 Health Care Providers.

June 21st, Thursday - Transcribe interviews. /Return to Santiago Sac., see patients with Guicha.

June 22nd, Friday - Interview 2 Health Care Providers.

June 23rd, Saturday – Confirm interviews for next week. / Travel to Tecpan.

June 24th, Sunday - *Rest*

June 25th, Monday - Interview 2 Health Care Providers.

June 26th, Tuesday - Transcribe interviews.

June 27th, Wednesday - Interview 2 Health Care Providers.

June 28th, Thursday - Transcribe interviews. /Return to Santiago Sac., see patients with Guicha.

June 29th, Friday - Interview 2 Health Care Providers.

June 30th, Saturday - Transcribe interviews. / Travel to San Lucas Toliman.

July 1st, Sunday - *Rest*

July 2nd, Monday - Interview 2 Health Care Providers.

July 3rd, Tuesday - Transcribe interviews.

July 4th, Wednesday - Interview 2 Health Care Providers.

July 5th, Thursday - Interview 2 Health Care Providers.

July 6th – 8th - Visit Maya Ruins.

July 9th – July 14th - Kaqchikel Lessons.

July 15th, Sunday - Guatemala Departure.

July 16th – July 28th – Kansas City, Kansas. Complete coding of interviews and entering into database. Analyze results.

Methods

Purpose of Study: This study will explore health care providers' knowledge, attitudes, and care approaches for diabetes in four indigenous Guatemalan villages. These results will be used to develop a set of quality improvement goals and objectives for patient management in each of the four clinical settings.

Data Collection: I will use qualitative research methods in this study with an accompanying Kaqchikel Maya translator when needed. I will carry out interviews with approximately twenty-four health care providers in four rural communities Santiago Sacatepéquez, San Juan Comalapa, Tecpan, and San Lucas Toliman. There will be interviews with six health care providers from each community. Health care providers will be through previous contacts and health clinic affiliates such as San Lucas Toliman Mission Clinic, ACOTCHI clinics in San Juan Comalapa and Tecpan, friend and community worker Guicha Ixcajuac of Santiago Sacatepéquez, and others listed below. I will not be listing the names of the study participants to preserve anonymity but each participant is affiliated with one of the listed resources below.

Each interview will be in an informal setting with the qualitative survey attached below. This survey is in Spanish for the literacy of the translator, but interviews will be conducted in Kaqchikel Maya when appropriate. The survey content was composed based on past research methods and anthropological studies in my undergraduate education at the University of Kansas. These questions are open to criticism and edits by my mentors prior to distribution in Guatemala. All interviews will be recorded and transcribed. I will transcribe each interview to avoid personal bias in future data analysis. With each coded/transcribed interview, my mentor (as well as other colleagues) will be able to observe the results of this study.

Potential Challenges:

Guatemala is a developing country with daily obstacles not only to my research, but to individuals' transportation and routines. This study will be conducted in the wet season when mudslides are not uncommon and fluctuation in gang-related violence can pose barriers to travel. The number of study participants might vary based upon their availability and potential conflicts. I plan on a study sample of approximately twenty-four participants with six participants from each community. I would like the six participants of the community to include various health care providers such as two pharmacists or natural healers, two nurses, and two midwives. These numbers of health care providers will likely vary in each community not only due to potential conflicts in travel and scheduling, but also due to the demographics of each community as I mentioned above. Also, I am not a fluent Kaqchikel Maya speaker and this will create some discrepancy in the survey results. To avoid misinterpretations, I will be coding the interviews. To ensure efficient translation of the Spanish survey to Kaqchikel Maya, I will spend time confirming the correct translations with a native Kaqchikel Maya speaker.

Mentors:

Dr. Peter Rohloff

Medical Director, Wuqu' Kawoq Clinical Fellow, Harvard Medical School

Dr. Allen Greiner

Family Medicine Research Division Associate Professor

University of Kansas School of Medicine

Health Care Provider Contacts*:

Asociación Civil de Comadronas Tradicionales de Chimaltenango (ACOTCHI)

(Traditional Midwives Association of Chimaltenango)

Chimaltenango Department

<http://www.acotchi.org>

Erika Yax

Head Midwife in ACOTCHI Clinic of San Juan Comalapa, Chimaltenango, Guatemala

Phone: (502) 5206 – 2423

Rodrigo Hernandez

ACOTCHI Coordinator

Yolanda Mux

Head Midwife in ACOTCHI Clinic of Tecpan, Chimaltenango, Guatemala

Herlinda Ic

Nurse working in the Chimaltenango Department Region

Guicha Ixcajuac

Community Health Worker in Santiago Sacatepequez

Maria Ticun

Midwife in Santiago Sacatepequez

Dr. Rafael Guizar

Physician in Chimaltenango Department

Dr. Augustin Rodriguez

Physician in Chimaltenango Department\ Medical Director of Companero de Salud

Florencio Cali

Site Director and Coordinator

(Contact for pharmacists in the four communities).

- **San Lucas Mission**
Kathy Huebert
La Parroquia
San Lucas Tolimán
Sololá 07013
Guatemala
CENTRAL AMERICA

<http://www.sanlucasmission.org/healthcare.php>

*With the above contacts I will contact affiliated midwives, nurses, and collaborating physicians (most I have collaborated with in past research). The participants of this study are not listed to preserve anonymity but are affiliated with the listed organizations/clinics.

Travel Contacts:

Florencio Cali

Site Director and Coordinator

Ernesto Lopez

Owner of Travel Services

Kaqchikel Maya Translators (if needed):

Magda (San Juan Comalapa)

Juan Ajsavinac (Patzun)

Rony Otzoy Chipix (San Juan Comalapa)

Teachers for Kaqchikel Maya Lessons:

Rafael Hernandez Huit

Filiberto Patal

Magda (San Juan Comalapa)

Juan Ajsavinac (Patzun)

Rony Otzoy Chipix (San Juan Comalapa) P

Lodging:

Wuqu' Kawoq Clinic 2 calle 5-43 zona

1 Santiago Sacatepéquez Guatemala 03006 Central America

Casa Luna, Antigua

Magda's home, San Juan Comalapa

Florencio Cali's home, Tecpan

Type 2 Diabetes Mellitus in Guatemala:
Survey of Knowledge, Attitudes, and Practices of Health Promoters

Date: ____/____/____

Information to read to respondent:

The purpose of this survey is to learn about your knowledge, attitudes and practices regarding diet and treatment for diabetes (DM). Your answers will not be given to anyone and your identity will remain anonymous. Your participation is voluntary and you may choose to stop the interview at any time.

Thank you.

For the Interviewer:

Please circle the selected answers(s). Do not read responses unless instructions indicate you to do so.

General and Demographic Information

AGE: _____

GENDER: Male/Female (Circle One).

JOB TITLE: (Circle One).

- a. Midwife
- b. Nurse
- c. Pharmacist
- d. Natural Healer
- e. Physician

1. How many years of experience do you have in this occupation? _____

2. Where did you receive your education and how many years was the program?

3. What languages do you speak? (Check all that apply).

- a. Kaqchikel
- b. K'ichee'
- c. Spanish
- d. English
- e. Others: _____

4. Are you able to read or write in any of those languages?

- a. Yes, _____
- b. No

DM Treatment, Diet Awareness and Knowledge Questions

- 5. In your opinion, how serious is DM?
 - a. Very serious
 - b. Somewhat serious
 - c. Not very serious
 - d. I don't know
- 6. What symptoms does the diabetic patient complain of normally?
- 7. In your opinion, can anyone get DM?
- 8. How or why does a person get DM?
- 9. What treatments do you provide to a person with diabetes?
- 10. Do these treatments cure DM?
 - a. Yes
 - b. No
- 11. How much does it cost for diagnosis and treatment?
- 12. How often do diabetic patients seek treatment from you?
- 13. How often do patients return for treatment?
- 14. What are some reasons patients do not return for treatment?
- 15. Does diet affect a person with DM?
 - a. Yes
 - b. No
- 16. If yes, how can diet affect a person with DM?
- 17. How do you explain the illness DM to your patients?
- 18. Explain what else you know about DM.

Thank you very much for your participation in this survey.

La Diabetes Mellitus en Guatemala:**Encuesta de Conocimiento, Actitudes, y Practicas de los promotores de salud**

FECHA:

Leer al promotor de salud:

El objetivo de esta entrevista es para aprender más de sus conocimientos, actitudes, y prácticas asunto de la dieta y de la diabetes. Su respuesta y su identidad serán anónimas. Su participación es voluntaria y se puede parar la encuesta en cualquier momento si usted quiere.

Gracias!

Entrevistadora:

Por favor, marque la respuesta escogida. Sólo lea las opciones cuando las instrucciones le indican hacerlo.

Información General

NOMBRE:**EDAD:****SEXO:****Ocupación:**

- a. Comadrona
- b. Enfermera
- c. Farmacéutico
- d. Naturista
- e. Médico

1. ¿Cuántos años de experiencia ha tenido en esta ocupación?_____
2. ¿Dónde recibió su educación y por cuánto tiempo has estudiado para cumplir su educación?
3. ¿Cuáles idiomas habla usted?
 - a. Kaqchikel
 - b. K'ichee'
 - c. Español
 - d. Ingles
 - e. Otros:_____
4. ¿Sabe leer o escribir? ¿En cuales idiomas?
 - a. Sí, _____
 - b. No

Tratamiento, Dieta y Conocimientos sobre la Diabetes

5. ¿En su opinión, que tan grave es la diabetes?
 - a. Muy grave
 - b. Grave
 - c. No es muy grave
 - d. Saber
6. ¿Cuáles son los síntomas que molestan a los diabéticos normalmente?
7. ¿En su opinión, a quienes les pega la diabetes?
8. ¿Por qué le pega a uno la diabetes?
9. ¿Cuáles son los tratamientos que dan a los diabéticos?
10. ¿Se puede curar la diabetes?
 - a. Sí
 - b. No
11. ¿Cuánto vale el tratamiento?
12. ¿Qué le hizo buscar tratamiento para la diabetes? ¿Cuánto tiempo pasó antes de que buscó tratamiento?
13. ¿Cuánto tiempo pasó hasta que el paciente vuelve otra vez para su tratamiento?
14. ¿Cuáles son las razones que los pacientes no regresan?
15. ¿Le afecta al diabético la dieta?
 - a. Sí (Véase la pregunta 16).
 - b. No
16. ¿Cómo afecta la dieta?
17. ¿Cómo se explica a la paciente acerca de la diabetes?
18. ¿Qué más ha oído o aprendido de la diabetes?

Muchas gracias por su participación en esta entrevista.

Budget:

Airline Ticket	\$782.50
Kaqchikel Maya Translator	\$200.00
Lodging and Meals	\$800.00
Airport Pick-up/Drop-off Transportation	\$60.00
Other Transportation*	\$500.00
Kaqchikel Maya Teacher	\$200.00
Total	\$2542.50

*Transportation fees will depend on current state of gang-related violence on chicken-bus travel. This number is currently conservative in presumption travel will more expensive and coordinated through Ernesto Lopez for safety issues.

Bibliography:

Greiner, M., Chary, A., Bowers, C., and Rohloff, P. *Managing Type 2 Diabetes in Indigenous Patients from Rural Guatemala: Report of a Pilot Study*. (Paper to be presented at the NAISA Conference 2012).

Stewart, Gloria López, Tambascia, Marcos, Guzman, Juan Rosas, Etchegoyen, Carrion, Jorge Ortega, and Artemenko, Sofia. *Control of Type 2 Diabetes mellitus among general practitioners in private practice in nine countries in Latin America*.

Kolling, Marie, Winkley, Kirsty, and Mette von Deden. *For Someone who's rich, it's not a problem: Insights from Tanzania on diabetes health-seeking and medical pluralism among Dar es Salaam's urban poor*.

Nueva, V. No title. Blood Pressure.

Torun, B. et al. *Rural to urban migration and cardiovascular disease risk factors in young Guatemalan adults*. International Journal of Epidemiology.

Montegro, R.A. and Stephens, C. *Indigenous Health in Latin America and the Caribbean.. 1859-1869* (2006).

Health System Innovations in Central America: Lessons and Impact of New Approaches World Bank Working Paper No. 57 edited by Gerard M. La Forgia.

Mbeh, George N., Edwards, Richard, Ngufor, George, Assah, Felix, Fezeu, Leopold, and Mbanya, Jean-Claude. *Traditional Healers and Diabetes: Results from a Pilot Project to train traditional healers to provide health education and appropriate health care practices for diabetes patients in Cameroon*. Journal Global Health Promotion.

Healthcare and the Role of the Orthodox Church in Byzantium

Brady B. Lonergan

Introduction:

This project considers the healing role of the Orthodox Church in Byzantium in the absence of a modern, somewhat more secularized medical infrastructure. Additionally, I hope to establish the Byzantine conceptualization of disease and its pathogenesis as a catalyst for the Church's involvement in healthcare. Along with a discussion of the relation between the Orthodox Church and medicine, I will also provide an overview of Byzantine medical techniques, technology and pharmacology as well as a description of available institutions and their systems of administration. In conjunction with a brief comparison between secular Islamic medicine and Byzantine medicine, this medico-historical survey will provide the context necessary to appreciate the extent of the Orthodox Church's involvement. A note of caution: throughout this proposal, I will use the terms Byzantine and Orthodox interchangeably; for our purposes, they can be considered synonymous.

Background:

Quite plainly, this proposed project combines my two strongest interests: medicine and Byzantium. Early on in my education, I developed a fondness for both history and the basic sciences. As time went on, my appreciation for the two fields of study became more refined. By my junior year of high school, while my fascination with history still lacked focus, my interest in science had become a desire to study medicine. Once in college, I began fulfilling my premed requirements and decided to enroll in a course on ethnography in Greek and Roman classics. Shortly thereafter, I realized that although medicine remained my ultimate goal, the classics department was where I wanted to be.

So, one course led to another, and I quickly found myself declaring a major in Classical Civilizations. But, what began as an appreciation for Greco-Roman history and the ancient Mediterranean eventually became a much more focused fascination with the continuation of everything Greek and Roman in the guise of the Byzantine Empire. The catalyst for this change was Professor Andrew Ekonomou's course on Byzantine history at Emory University. His course served as my introduction to the topic and led to my enrollment in Penn professor Robert Ousterhout's undergraduate and graduate courses on Byzantine art history.

At first glance, a treatise on the role of religion in Byzantine healing may seem inapplicable and even esoteric to an audience composed primarily of medical students and healthcare professionals. Yes, I could argue that this project is relevant to the extent that it does exhibit grounding in medical science and the history of medicine. But, more importantly, I would argue that the greatest potential inherent in this project is its ability to enhance our understanding of the role religion and spirituality still play in our healthcare system today.

Despite the technical and technological progress made between now and the fall of Constantinople, religion still remains. As a result, many of the same attitudes persist, albeit in slightly different forms.

Although we live in an age of reason, we continue to cross our fingers and pray for health and happiness. In fact, one might argue that as long as disease and infirmity exist, religion will continue to play a role in healing. Put another way, until our own knowledge and understanding of the world become absolute, religion will remain an important aspect of everyday life.

So, as medical professionals intent on providing patient oriented care, we will all encounter the religious beliefs of others. And, regardless of our own beliefs, it is important that we understand the role the patient prefers religion to play in his or her healthcare. As such, with this paper, I hope to provide some insight into the relation between religion and medicine that still exists today.

Description:

In this paper, I will focus on the healthcare providing role of the Orthodox Church in the context of contemporary Byzantine medical techniques, technology and infrastructure.

I. Overview of Byzantine medical techniques and technology:

In order to provide some historical context, my paper will begin with an overview of medicine in Byzantium. Given the amount of time available for research, this treatment will consist of a relatively definitive condensation of the available literature. This portion of the paper will include details on medical techniques and technology as well as pharmacology and the extent of specialization available. For example, diagnostic procedures like uroscopy will be discussed. Also included will be a breakdown of the various types of medical professionals, from the common barber-surgeons to the classically trained physicians of Constantinople. Furthermore, I will address the presence, capacity and character of medical institutions such as hospitals, hospices and centers of learning. Additionally, as the evidence allows, I will provide concrete examples of individual physicians whose contribution to the medical literature of the time have survived as well as specific examples of healthcare institutions in the Empire. And finally, I will include an evaluation of payment for services rendered and to what extent healthcare was a private expense, government funded or both.

Baldwin, Barry. "Beyond the House Call: Doctors in Early Byzantine History and Politics."

Dumbarton Oaks Papers 38 (1984): 15-19.

Bliquez, Lawrence J. "Two Lists of Greek Surgical Instruments and the State of Surgery in

Byzantine Times." *Dumbarton Oaks Papers* 38 (1984): 187-204.

Campbell, Sheila, Bert Hall and David Klausner, eds. *Health, Disease and Healing in Medieval Culture*.

New York: St. Martin's Press, 1992.

Dols, Michael W. *Medieval Islamic Medicine: Ibn Ridwan's Treatise, "On the Prevention of Bodily Ills in*

Egypt". Berkeley : University of California Press, 1984.

- Duffy, John. "Byzantine Medicine in the Sixth and Seventh Centuries: Aspects of Teaching and Practice." *Dumbarton Oaks Papers* 38 (1984): 21-27.
- Givens, Jean A., Karen M. Reeds and Alain Touwaide, eds. *Visualizing Medieval Medicine and Natural History, 1200-1550*. Burlington: Ashgate Publishing Co., 2006.
- Hohlweg, Armin. "John Actuarius' 'De methodo medendi'-On the New Edition." *Dumbarton Oaks Papers* 38 (1984): 121-133.
- Kazhdan, A. "The Image of the Medical Doctor in Byzantine Literature of the Tenth to Twelfth Centuries." *Dumbarton Oaks Papers* 38 (1984): 43-51.
- Lieber, Elinor. "Asaf's 'Book of Medicines': A Hebrew Encyclopedia of Greek and Jewish Medicine, Possibly Compiled in Byzantium on an Indian Model." *Dumbarton Oaks Papers* 38 (1984): 233-249.
- Nutton, Vivian. *Ancient Medicine*. London: Routledge, 2004.
- Nutton, Vivian. "From Galen to Alexander, Aspects of Medicine and Medical Practice in Late Antiquity." *Dumbarton Oaks Papers* 38 (1984): 1-14.
- Pormann, Peter E. *Medieval Islamic Medicine*. Washington, D.C.: Georgetown University Press, 2007.
- Pioreschi, Plinio. *A History of Medicine: Vol. IV, Byzantine and Islamic Medicine*. New York: Edwin Mellen Press, 2001.
- Renahan, Robert. "Meletius' Chapter on the Eyes: An Unidentified Source." *Dumbarton Oaks Papers* 38 (1984): 159-168.
- Riddle, John M. "Byzantine Commentaries on Dioscorides." *Dumbarton Oaks Papers* 38 (1984): 95-102.
- Savage-Smith, Emilie. "Hellenistic and Byzantine Ophthalmology: Trachoma and Sequelae." *Dumbarton Oaks Papers* 38 (1984): 169-186.
- Scarborough, John. "Early Byzantine Pharmacology." *Dumbarton Oaks Papers* 38 (1984): 213-

232.

Scarborough, John. "Symposium on Byzantine Medicine: Introduction." *Dumbarton Oaks Papers* 38 (1984): 9-16.

Sonderkamp, Joseph A. M. "Theophanes Nonnus: Medicine in the Circle of Constantine Porphyrogenitus." *Dumbarton Oaks Papers* 38 (1984): 29-41.

Stannard, Jerry. "Aspects of Byzantine Materia Medica." *Dumbarton Oaks Papers* 38 (1984): 205-211.

Temkin, Owsei. "Byzantine Medicine, Tradition and Empiricism," *DOP* 16 (1962) 95-115.

Theodorides, Jean. "Rabies in Byzantine Medicine." *Dumbarton Oaks Papers* 38 (1984): 149-158.

Todd, Robert B. "Philosophy and Medicine in John Philoponus' Commentary on Aristotle's 'De Anima'." *Dumbarton Oaks Papers* 38 (1984): 103-110.

Wallis, Faith, ed. *Medieval Medicine: A Reader*. Toronto: University of Toronto Press, 2010.

Ziegler, Joseph. *Medieval Medicine c. 1300*. Oxford: Clarendon Press, 1998.

Following this general survey, the bulk of my paper will be devoted to assessing the role played by the Orthodox Church and its clergy.

II. The development of the hospital in Byzantium:

What role(s) did the first hospitals play? Were there different types of hospitals? Did particular hospitals specialize in a specific area of treatment? If so, were patients referred from one hospital to another in order to provide appropriate care? Were hospitals in Constantinople or Thessaloniki considered preferable to more provincial healthcare centers?

Was there a similar or related institution that preceded the hospital? How did the Byzantine hospital evolve over the course of the Empire's history? Did the hospital originate in a military setting? If not, what were the immediate needs that necessitated the establishment of an institution to complement the individual physicians and surgeons already in existence?

Where were hospitals generally located? Were they primarily urban, rural or both? If hospitals existed in both settings, were there differences in size, capacity and administration between urban and rural?

Who staffed the hospitals? Were hospital clerics generally monks? Were hospital clerics devoted to a specific order or holy figure? In addition to the clerical staff, did hospitals also employ a variety of health professionals (i.e. nurses, surgeons, physicians, specialists, etc.)?

What were the various manifestations of the hospital in Byzantium? Did they act primarily as institutions for inpatient care? Did they serve as centers for assisted living? Did they act as academic centers? Were they considered a place where people simply went to die; in other words, were they primarily centers of palliative care? Did they act to quarantine individuals with contagious disease? In short, what was the primary role of the hospital? Did it also play a number of secondary roles? Were there different types of institutions with different primary functions included in the category of hospital?

In hospitals, were patients divided according to their illness or prescribed treatment? With that, was there a prototypical layout used for most Byzantine hospitals? Were patients tended to primarily by physicians? Or was there an important role played by other professionals (i.e. nurses, social workers, orderlies, etc.)? Was there a hierarchy among the hospital staff?

How were hospitals funded? Were they state-run? Were they run solely by the Church and thus reliant upon private contributions as well as contributions from the emperor? Which individuals acted as hospitals administrators? Were they affiliated with the Orthodox Church? Were they physicians? Or, were they simply well-situated bureaucrats appointed by the emperor or another more provincial power? Were hospital patients charged a fee? If so, were they charged by the institution or by individual medical practitioners?

How did monasticism contribute to the development and evolution of the Byzantine hospital? As centers of learning, did they play an important role in medical education and application? Did monasteries and their monks play an active role in the provision of healthcare? If so, in what capacity did they function? Did they help staff and maintain facilities such as hospitals and centers for assisted living? Were hospitals built near a monastery or as part of a monastic complex? As somewhat autonomous entities, were monasteries and their monks free to develop their own style of healthcare? If so, how did the healthcare and hospitals affiliated with Orthodox monasticism differ from other non-monastic manifestations?

Were hospitals associated with other charitable organizations (i.e. orphanages, homeless shelters, etc.)? If so, did hospitals typically include such accommodations for the destitute?

What role did what we would today call non-traditional medicine play in the hospital setting? Were icons, relics or holy men and women typically relied upon in the hospital setting?

Which members of Byzantine society comprised the typical clientele of the imperial hospital? Were they civil servants? Were they soldiers? Were they poor? Were they rich? Or, did all strata of the Byzantine population seek medical care in these hospitals? Was practice of the Orthodox faith a prerequisite for treatment in one of these Byzantine hospitals? Were non-Christians or members of heretical sects turned away? Were the physicians staffing these hospitals predominantly Orthodox

Christian? Were there Muslim, Jewish or other religiously affiliated professionals associated with Byzantine hospitals?

How did Islamic hospitals compare to their Byzantine counterparts?

Baldwin, Barry. "Beyond the House Call: Doctors in Early Byzantine History and Politics."

Dumbarton Oaks Papers 38 (1984): 15-19.

Dols, Michael. "Insanity in Byzantine and Islamic Medicine." *Dumbarton Oaks Papers* 38

(1984): 135-148.

Duffy, John. "Byzantine Medicine in the Sixth and Seventh Centuries: Aspects of Teaching and

Practice." *Dumbarton Oaks Papers* 38 (1984): 21-27.

Miller, Timothy S. *The Birth of the Hospital in the Byzantine Empire*. Baltimore: The Johns Hopkins University Press, 1985.

Miller, Timothy S. "Byzantine Hospitals." *Dumbarton Oaks Papers* 38 (1984): 53-63.

Morris, Rosemary. *Monks and Laymen in Byzantium, 843-1118*. Cambridge: Cambridge University Press, 1995.

Pormann, Peter E. *Medieval Islamic Medicine*. Washington, D.C.: Georgetown University Press, 2007.

Prioreschi, Plinio. *A History of Medicine: Vol. IV, Byzantine and Islamic Medicine*. New York: Edwin Mellen Press, 2001.

III. The Orthodox Byzantine psyche and conceptualization of illness:

How did the Byzantines conceptualize disease and its pathogenesis? To what extent was the Byzantine understanding of disease processes dictated by their Orthodox faith? To what extent was their understanding inherited from Greco-Roman religious cult and paganism? How did the professional view of disease differ from that of the medical layman?

Did Byzantines consider evil spirits to be a principal cause of illness and infirmity? More specifically, was direct demonic possession considered necessary to cause disease? Could disease be attributed to benign spirits? Were primarily chronic illnesses rather than acute diseases considered the result of demonic possession? To what did contemporary Byzantines attribute their chronic illnesses to demonic possession? Was the belief in demonic possession as the cause of chronic illness subscribed to by secular medical practitioners? Did religiously affiliated medical practitioners share this belief? Or, was this belief held primarily by the patient population lacking medical education?

How did mental illness relate to the notion of demonic possession and to what extent was exorcism considered an appropriate treatment for chronic and/or mental illness? Which individuals were considered qualified to perform exorcisms? Did individual exorcisms have to be sanctioned by local Church leaders? Was clerical opinion necessary to make the diagnosis of demonic possession? Were treatments other than exorcism deemed appropriate? Was secular treatment used in concert with exorcism?

How did the Byzantine conception of the health of the soul relate to their understanding of mental and physical wellbeing? Was a healthy soul a prerequisite for a healthy mind and body? Could the former be mutually exclusive of the latter? In other words, could you have a healthy mind and body without a healthy soul? Conversely, could you have an ill mind or body with a healthy soul?

How did the view of demonic possession, the health of the soul and chronic illness affect treatment? Were secular approaches used solely for acute illnesses? Were chronic illnesses treated only by spiritual means? Were non-Christian, non-traditional (i.e. magical) approaches ever used? To what extent was magic deemed an appropriate means of treatment? Did physicians use magic or items associated with magic (i.e. amulets) because they themselves believed in their efficacy or because their patients did?

How did the Byzantine understanding of disease and its causes invite the involvement of the Orthodox Church? If physical and mental wellbeing was believed to be a reflection of spiritual wellbeing, was the role of the Church in the administration of healthcare inevitable? Was the involvement of religion a new phenomenon, or are there examples of pre-Christian religious healing in the Roman Empire?

How did the Islamic conceptualization of disease and its pathogenesis compare to that of the Byzantine? Specifically, how did Islamic medical professionals approach the question of chronic and/or mental illness? Did they subscribe to any similar belief system regarding demonic possession?

Dols, Michael. "Insanity in Byzantine and Islamic Medicine." *Dumbarton Oaks Papers* 38

(1984): 135-148.

Frenkel, Miriam and Yaacov Lev, eds. *Charity and Giving in Monotheistic Religion*. Berlin: Walter de Gruyter, 2009.

Harakas, Stanley S. *Health and Medicine in the Eastern Orthodox Tradition: Faith, Liturgy and Wholeness*. New York: Crossroad, 1990.

Nikolaides, E. *Science and Eastern Orthodoxy: from the Greek fathers to the Age of Globalization*. Trans.

Susan Emanuel. Baltimore: Johns Hopkins University Press, 2011.

Prioreschi, Plinio. *A History of Medicine: Vol. IV, Byzantine and Islamic Medicine*. New York:

Edwin Mellen Press, 2001.

Pormann, Peter E. *Medieval Islamic Medicine*. Washington, D.C.: Georgetown University Press, 2007.

Temkin, Owsei. *Hippocrates in a World of Pagans and Christians*. Baltimore: The Johns Hopkins University Press, 1991.

Todd, Robert B. "Philosophy and Medicine in John Philoponus' Commentary on Aristotle's 'De Anima'." *Dumbarton Oaks Papers* 38 (1984): 103-110.

IV. Miracles, saints (and holy men/women) and healing in the Eastern Orthodox traditions:

Miracles, particularly of healing, play an important role in the Eastern Orthodox tradition. Incidents of healing are an essential criterion for the canonization of saints in the Orthodox Church. As such, what role did saints play in the administration of healthcare? How does the hagiographical tradition depict the relationship between saints and secular medical professionals? Was this relationship one of antagonism? Or, did physicians and saints work in concert with one another for the benefit of the patient? By what means did saints perform their miracles of healing? Did healing require physical contact, general prayer or specific Orthodox incantations? Did saints require other intermediaries, or could they channel the divine power of healing directly? Was this a strenuous process on the part of the saint and/or his/her patient?

Although almost every saint is associated with healing, some are actually linked to medical practice in a more professional sense. Examples of physician-saints include Samson the Hospitable as well as the fraternal saints Damian and Cosmas. What were the characteristics common amongst these physician-saints? Did they reflect a professional ideal? And, more specifically, as saints already associated with the healing arts, were they sought after by the ill and infirm? In other words, did they and their relics and icons play a preeminent role in spiritual healing? Or, did they simply act as the patron saints of the living, working medical professionals throughout the Empire? To tie this to the present, it might also be interesting to consider the current criteria for canonization and the curriculum vitae of the Orthodox physician-saints of the modern era.

Pilgrimage was an important aspect of worship in the Orthodox Church, and Christians regularly visited shrines, tombs and other holy sites associated with particular religious figures and their relics. Oftentimes, as part of this religious experience, pilgrims would take with them either stamped tokens or ampullae filled with dirt from the site, holy oil or some other similar substance. For some, they may have served as simple souvenirs, but for most, these items were imbued with the power of the associated holy figure. So, what role, if any, did holy sites and their associated 'souvenirs' play in the administration of healthcare? If these tokens could be used as a means of healing, was contact with the actual object necessary for effective use? Did the holy substance (i.e. ground token, dirt, oil, etc.) need to be ingested to perform its healing function? For superficial injury, could these holy substances be

applied directly to the affected area? To what extent is the practice of direct application of these tokens influenced by the religious record of Christ's use of saliva or the laying on of hands to cure disease?

Monasticism was and still is an important element of Orthodox Christianity. As centers of learning and as somewhat autonomous entities, what role, if any, did monasteries and monastic communities play in Byzantine healthcare? If monasteries and their monks played an active role in the provision of medical care, in what capacity did they function? Did they staff and maintain facilities such as hospitals or centers for assisted living? Could monks act as physicians or surgeons? What relationship existed, if any, between monks and secular medical professionals? Was there a standing dialogue between secular and religious healers, which would allow referrals between the two groups?

As individuals who by way of prayer, meditation and social isolation were imbued with the power of the Holy Spirit, holy men and women were an important albeit marginalized element of Byzantine society. With such power, in what capacity, if any, did these individuals take part in the provision of healing? Also, practically speaking, since these men and women were more accessible than actual saints, did they play a more prominent role in healing? Did physicians and other secular medical professionals refer their patients to these holy healers? What was the professional relationship between these holy men and women and medical professionals?

What role, if any, did non-monastic clergymen play in the administration of healthcare? Were they caregivers? Were they administrators? In regards to healing, what relationship existed between the non-monastic clergy and both monasteries and secular medical professionals? Did these clergymen play an active healing role amongst their congregations? Or, did they refer individuals to monastic communities or secular professionals?

What does it mean to have healing as an expected function of a religion? Is this a universal aspect of all organized religion? Or, is it primarily associated with Judeo-Christian religion? Where does secular healing end and spiritual healing begin? Are the two mutually exclusive in the case of Byzantium? Were they generally antagonistic, or was there a sense of collegiality among the various types of healers? Were secular and religious treatments interchangeable, or did one supersede the other in certain cases? Was there any overlap among classically trained physicians and religious figures? In other words, could monks or other holy figures train as physicians, and could medical professionals include religious healing in their repertoire of medical expertise?

Dols, Michael. "Insanity in Byzantine and Islamic Medicine." *Dumbarton Oaks Papers* 38

(1984): 135-148.

Frenkel, Miriam and Yaacov Lev, eds. *Charity and Giving in Monotheistic Religion*. Berlin: Walter de Gruyter, 2009.

Hackel, Sergei, ed. *The Byzantine Saint*. Crestwood, NY: St. Vladimir's Seminary Press, 2001.

Harakas, Stanley S. *Health and Medicine in the Eastern Orthodox Tradition: Faith, Liturgy and*

Wholeness. New York: Crossroad, 1990.

Harvey, Susan A. "Physicians and Ascetics in John of Ephesus: An Expedient Alliance."

Dumbarton Oaks Papers 38 (1984): 87-93.

Maguire, Henry. *The Icons of their Bodies: Saints and their Images in Byzantium*. Princeton: Princeton University Press, 1996.

Morris, Rosemary. *Monks and Laymen in Byzantium, 843-1118*. Cambridge: Cambridge University Press, 1995.

Nikolaides, E. *Science and Eastern Orthodoxy: from the Greek fathers to the Age of Globalization*. Trans. Susan Emanuel. Baltimore: Johns Hopkins University Press, 2011.

Talbot, Alice-Mary, ed. *Byzantine Defenders of Images: Eight Saints' Lives in English Translation*. Washington, D.C.: Dumbarton Oaks Research Library and Collection, 1998.

Talbot, Alice-Mary. *Holy Women of Byzantium: Ten Saints' Lives in English Translation*. Washington, D.C.: Dumbarton Oaks Research Library and Collection, 1996.

Temkin, Owsei. *Hippocrates in a World of Pagans and Christians*. Baltimore: The Johns Hopkins University Press, 1991.

Vikan, Gary. "Art, Medicine, and Magic in Early Byzantium." *Dumbarton Oaks Papers* 38 (1984): 65-86.

V. The role of Orthodox iconography in healing:

What role, if any, did relics play in the administration of healthcare? If relics played an important role, how were they used? How were they perceived as tools for healing by patients? How were they perceived by physicians? How were they perceived by other medical professionals? If used by physicians, were they used because medical professionals believed in their effectiveness or simply because of the possibility of a placebo effect? Were they used in concert with more 'traditional' applications of healthcare?

Like relics, icons acted as media through which the devout could commune and even interact with the holy figure depicted. In this way, both could be likened to portals to the divine dimension, providing individual access to saints, Christ and the Mother of God. As such, what role, if any, did icons play in healing? Was this role comparable to that played by relics? Was one considered more effective than the other?

For both relics and icons, were associations with particular saints or holy figures more important? For instance, was an icon of a physician-saint deemed more effective or more appropriate than one of Saint George? Moreover, were icons of or relics associated with Christ or the Virgin Mary considered more potent than those of lesser holy figures?

Practically speaking, how were icons and relics used for healing? Did they simply facilitate communion with a particular holy figure? Was physical contact with the relic or icon an important aspect of the healing process? Was ingestion of any part or product of a relic or icon necessary to access the healing power of the divine? Was the vocalization of prayers essential? Or, could prayers remain silent? Was communal prayer with the relic or icon among patient, physician and family necessary?

Belting, Hans. *The Image and Its Public in the Middle Ages: Form and Function of Early Paintings of the*

Passion. Trans. Mark Bartusis and Raymond Meyer. New Rochelle: A.D. Caratzas, 1990.

Carr, Annmarie Weyl. *Imprinting the Divine: Byzantine and Russian Icons from the Menil Collection*.

New Haven: Yale University Press, 2011.

Eastmond, Antony and Liz James, eds. *Icon and Word: the Power of Images in Byzantium*. Burlington,

VT: Ashgate, 2003.

Freeman, Charles. *Holy Bones, Holy Dust: How Relics Shaped the History of Medieval Europe*. New

Haven: Yale University Press, 2011.

Harakas, Stanley S. *Health and Medicine in the Eastern Orthodox Tradition: Faith, Liturgy and*

Wholeness. New York: Crossroad, 1990.

Hetherington, Paul. *Enamels, Crowns, Relics and Icons: Studies on Luxury Arts in Byzantium*. Burlington,

VT: Ashgate, 2008.

Maguire, Henry. *The Icons of their Bodies: Saints and their Images in Byzantium*. Princeton: Princeton

University Press, 1996.

Ousterhout, Robert and Leslie Brubaker, eds. *The Sacred Image East and West*. Urbana: University of

Illinois Press, 1995.

Pentcheva, Bissera V. *Icons and Power: the Mother of God in Byzantium*. University Park: Pennsylvania

State University Press, 2006.

Pentcheva, Bissera V. *The Sensual Icon: Space, Ritual, and the Senses in Byzantium*. University Park:

Pennsylvania State University Press, 2010.

Rice, David Talbot. *Byzantine Icons*. London: Faber and Faber, 1959.

Talbot, Alice-Mary, ed. *Byzantine Defenders of Images: Eight Saints' Lives in English Translation*.

Washington, D.C.: Dumbarton Oaks Research Library and Collection, 1998.

Temkin, Owsei. *Hippocrates in a World of Pagans and Christians*. Baltimore: The Johns Hopkins University Press, 1991.

Vikan, Gary. "Art, Medicine, and Magic in Early Byzantium." *Dumbarton Oaks Papers* 38 (1984): 65-86.

I will conclude with my own thoughts regarding the parallels that can be drawn between the association of religion and medicine then and now. In short, I will take a brief look at how medicine today is influenced by religion. This portion would be based on my own perspective and experience as a medical student here at the University of Kansas. In this way, I will direct the reader's attention towards a consideration of the dynamic stasis (or static dynamism) of medicine and its relation to religion.

Timeline:

My time will be spent among my apartment, the Clendenen Library and the libraries on the Lawrence Campus. Although I will carry out a great deal of my research on the two campuses, I will spend the majority of my time working from home. In addition to my review of the literature, I will also set aside time to visit two Greek Orthodox churches in the area: St Dionysios in Overland Park, KS and Annunciation in Kansas City, MO. Below is a working timeline for my project:

May 27th to June 6th-Research section I and prepare a summary of the pertinent information.

June 7th to June 16th-Research section II and prepare a summary of the pertinent information.

June 17th to June 26th-Research section III and prepare a summary of the pertinent information.

June 27th to July 6th-Research section IV and prepare a summary of the pertinent information (Visit St Dionysios and meet with a church representative).

June July 7th to July 17th-Research section V and prepare a summary of the pertinent information (Visit Annunciation and meet with a church representative).

July 18th to July 21st-Outline the paper.

July 22nd to July 25th-Write a preliminary draft of the paper.

July 26th to July 28th-Make revisions and produce a polished draft.

Post-July 28th-Make additional revisions if needed.

Methods:

Most of my project will consist of literature review. As such, to complete my project, I will take advantage of the resources made available by the University of Kansas libraries. In addition to the collection of books and journals on both campuses, I will rely heavily on the online journal database JSTOR as well as interlibrary loan whenever necessary. Because I have access to a relatively reliable vehicle, I do not foresee any obstacles to my use of campus resources.

Contacts:

In addition to my faculty mentor, my primary contacts in this endeavor will be Dr. Andrew Ekonomou, PhD, a former lecturer on Byzantine history and literature at Emory University and Dr. Robert Ousterhout, PhD, a professor of Byzantine art and architectural history at the University of Pennsylvania.

Dr. Andrew Ekonomou

Dr. Robert Ousterhout

Budget:

My expenses will consist of the cost of transportation between Kansas City and Lawrence as well as the cost of transportation to and from the Annunciation and St Dionysios Greek Orthodox Christian Churches in Kansas City.

Jewish Genetic Screening:

An evaluation of the barriers to utilization and
strategies to increase the awareness of young
Jewish adults

Rachel Myers

University of Kansas School of Medicine 2015

Clendening Fellowship

February 13, 2012

Introduction:

Genetic screening in the Ashkenazi Jewish population began in the 1970s with Tay-Sachs disease (TSD) and through its education and counseling efforts has reduced the birth rate of infants with TSD within the Ashkenazi Jewish community by 90% (Schneider). The successful screening programs have incorporated significant education and counseling efforts. Currently, screening is available to test for approximately 16 genetic disorders, four of which (cystic fibrosis, TSD, Canavan disease and dysautonomia) are considered the standard of care (Hegwer). Because TSD screening has been so successful at reducing the numbers of Jewish children born with TSD, many Jews are unaware that they are at increased risk to have an affected child. Ashkenazi Jews have an approximately 14% chance of carrying one of the conditions (Heger). One approach to reducing the risk for having an affected child was established through a program called Dor Yeshorim. Established in 1983, Dor Yeshorim is a program for ultra-orthodox couples who have arranged marriages. It provides pre-marital, anonymous, confidential carrier screening for nine conditions (Loannou). The goal is to avoid an arranged marriage between individuals who are carriers for the same autosomal recessive condition, thereby eliminating the chance for an affected child.

Some controversy has arisen regarding the appropriate timing of screening and the level of participants' knowledge. Though most agree preconception screening is ideal, appropriate timing (i.e. high school, college, early adulthood, pre or post-marital) is still unresolved (Hegner). Screening programs in Jewish high schools in Canada and Australia found that greater levels of knowledge were associated with fewer negative feelings toward the screening process, less anxiety if found to be a carrier, and greater preparation to address future reproductive options. However, others argue that knowledge of one's carrier status may not be relevant or remembered when screening is performed at younger ages, that high school students cannot be adequately informed to give consent, and that the accompanying social stigmas or psychological stress may be too overwhelming (Loannou).

It is apparent that education is a critical factor in any effort aimed at eliminating these preventable disorders, especially as the numbers of Jews with unknown family ancestry continue to increase. These challenges to successful carrier screening in the Jewish community are currently being addressed through the education, screening and prevention programs of the Chicago Center for Jewish Genetic Disorders. The Chicago Center strives to increase awareness of Jewish genetic disorders for the Jewish community, health care providers, religious figures and the general public. In addition to their ongoing work, my research project findings may be used by healthcare providers and other non-profit agencies to more effectively approach and respond to patients.

Background:

The exposure to several Jewish genetic diseases during the Genetics & Neoplasia module, coupled with my personal experience as a member of the Conservative Jewish community, has driven my desire to explore the prevention and management of these disorders in greater detail. After discussing this subject matter with my parents, I learned that they had carrier screening for

TSD prior to conception. Though their tests were negative, I am curious as to how others proceed if one or both members of the couple are found to be carriers, particularly in light of the fact that 14% of participants in screening programs will be carriers of one of the conditions, and 2% screened will be at risk for a child with one of the conditions. In addition to having several friends and family members who are carriers of Jewish genetic diseases, I also have had a long-standing career interest in preventative health and endocrinology, and feel this would be a prime opportunity to explore the reproductive component of the specialty. Though prevalence remains low, no Jewish parent should have to experience the tragedy of having an affected child given the ease with which individuals at risk to have children with these untreatable disorders can be identified.

As an undergrad I completed a medical ethics class, which explored topics such as genetic testing and abortion. Unfortunately, the professor did not address most religious concerns. Outside of class while shadowing an oncologist, I obtained a profound appreciation for the importance of an empathetic, supportive patient-physician interaction that can only be taught through observation and experience. Finally, because this project requires a large Jewish population, I have chosen to do part of the research in Chicago where I have family and friends who will be of assistance with living arrangements. Of additional importance is the fact that Chicago has the closest Dor Yeshorim testing center.

Goals/ objectives:

Screening programs have dramatically reduced the incidence of Jewish genetic disorders. Nevertheless, questions still remain regarding the age at which testing is most appropriate, how much information is required to make informed choices, and the ideal level of education needed to maximize participating while minimizing feelings of fear and hopelessness. It is my goal to determine how the level of awareness and screening rates can be improved among orthodox, conservation and reform Jews. I hope to determine how physicians, counselors and religious figures can maximize their role for the varying Jewish denominations regarding education and prevention, while determining the appropriate time to be screened. Because screening has become so effective, interest in educational programming and screening has declined. I hope to identify those factors which will revive interest in Jewish genetic screening, particularly in the Kansas City area.

For those who undergo screening, I plan to study their motivations for screening at that time, as well as any drawbacks to that timing. This will include any social, psychological and financial concerns. I also hope to assess individuals' perception of their carrier status and how they choose to proceed given their carrier status. I hope to determine the ideal time for screening, acquisition of an appropriate knowledge base, and any other potential improvements which may be made to the screening process. Overall, the project will allow me to gain a better understanding of the issues and current controversies, raise awareness and better prepare me for a future in medicine.

Timeline:

- a. Late May to early June (Kansas City): preliminary research, i.e. literature review, conducting interviews with local rabbis, genetic counselors, and patients

- b. Early June to early July (Chicago): interview patients during the mass-screening at Children's Memorial Hospital, interview former patients from the February and April mass screenings, interview counselors and rabbis, collect data at the Chicago Center
- c. Early July to late July (Kansas City): continue patient and rabbi interviews as needed, analyze data and interview responses for research paper

Methods:

Prior to the summer, I plan to continue reading the history and development of Jewish genetic screening. The Chicago Center for Jewish Genetic Disorders has agreed to allow me to conduct research at their office on their interdisciplinary prevention and educational programming techniques. To achieve these goals, I will be conducting interviews during a mass screening in mid-June with approximately 45 participants of Dr. Joel Charrow and Ms. Michelle Gilats at Children's Memorial Hospital. These interviews will occur between the educational presentations and screening appointments. After participants sign up for the mass screening in March, I will send a letter of introduction, as well as a list of questions. This will allow participants to consider their answers before the face-to-face interview. Should time not allow for all interviews, I will arrange follow up meetings with participants. I will also contact past participants from the January and March mass screenings, consisting of approximately 40 participants each, to obtain a larger population base. Finally, a small advertisement in the Kansas City Jewish Chronicle seeking additional interviewees who have had genetic testing has generated a significant number of responses.

In addition to interviewing patients, I will interview physicians, counselors, religious figures and staff members at the Center both before and after the mass screening to identify the current educational opportunities for families and the barriers to screening. I have also identified over a dozen rabbis from the Orthodox, Conservative and Reform movements, in both the Chicago and Kansas City areas, who have agreed to participate in the project. I also will observe physicians and counselors working with patients in order to gain a better understanding of patients' experiences and to document the strategies used.

When not conducting interviews, I will be assisting the Chicago Center with their prevention strategies. I will also attend educational programming and talk to attendees in order to identify concerns, potential for improvements and their overall response. Michael Begleiter, a genetic counselor at Children's Mercy Hospital in Kansas City, MO, has also agreed to serve as a mentor and help me in whatever capacity is necessary. I will spend the last two weeks analyzing data, compiling the research, creating a presentation and providing feedback to counselors. Analysis will include all aspects of the interview and observation, including demographic information, attitudes and beliefs. Should time allow, I would also like to work on my own educational programming effort most likely targeting college campuses.

Throughout the spring, I will continue to contact counselors, patients and religious figures asking for their cooperation on the project. Due to the importance of education, all clinics, non-profit agencies and religious organizations which I have contacted thus far have expressed excitement with the project, willingness to contribute and interest in the results. The time frame for the project is rather fluid due to my flexible living arrangements in both locations and the possibility that I may lose and add potential

interviewees. Timing will largely depend on when it is most convenient for individuals to meet, scheduling of counseling appointments, and the Center's programming efforts throughout the summer. I am awaiting feedback on my Application for Except Review of Human Subject Research through KUMC, as well as waiting for information from Michelle Gilats regarding obtaining IRB approval through Children's Memorial Hospital. She does not anticipate any problems with approval, as participants in the mass genetic screening are not considered Children's patients, and interviews are typically exempt from the IRB approval process.

Contacts:

Chicago Center for Jewish Genetic Disorders Ben Gurion Way 30 S. Wells St. Chicago, IL 60606	Karen Litwack, director
	Michelle Gilats, licensed genetic counselor
	Dr. Joel Charrow, M.D. scientific advisor
Children's Mercy Hospital 2401 Gillham Road Kansas City , MO 64108	Michael Begleiter, M.S. CGC
The following includes rabbis and other community figures from varying denominations who have agreed to help with the study thus far:	Kansas City: Rabbi Nemitoff, Rabbi Itkin, Chana Itkin, Rabbi Cohen, Rabbi Schuster, Jay Lewis, Rabbi Rockoff
	Chicago: Rabbi Mendel, Rabbi Siegel, Rabbi Conover, Rabbi Sandmel, Rabbi Flinkenstein, Rabbi Moscowitz, Rabbi Zedek, Alison Lewin, Rabbi Lopatin

Conclusion:

Most importantly, this project will benefit the greater Jewish community by assessing how education and prevention efforts can be received with more enthusiasm. In addition to identifying methods through which awareness can be improved, the research will benefit patients participating in screening by assessing optimal timing and level of knowledge. The findings can also be applied to other clinics and non-profit agencies in promoting awareness. The project will supplement my education as a medical student and future clinician by providing exposure to a field of interest, allowing me to acquire a greater sense of patient concerns and cultural differences and experience patients coping with sensitive subject matter. Finally, I would like to thank the Clendening Fellowship Program for allowing me the opportunity to explore an unconventional, yet meaningful humanitarian-based issue within the medical field.

Budget:

- a. Round trip transportation to and from Chicago: \$300

- b. Transportation in Chicago and Kansas City (e.g. gas, parking, public transit): \$300 per month
- c. 30-day unlimited Chicago Transit Authority (CTA) pass: \$86
- d. Rent: no charge (provided by friends and family in Chicago)
- e. Food: \$300 per month
- f. Printing and mailing costs: \$100
- g. Thank you gifts for the Center, counselors and interviewees: \$200

Works cited:

1. Hegwer, G., C. Fairley, J. Charrow, and K. E. Ormond. "Knowledge and Attitudes Toward a Free Education and Ashkenazi Jewish Carrier Testing Program." *Journal of Genetic Counseling* 15.1 (2006): 61-70.
2. Ioannou, L., J. Massie, S. Lewis, V. Petrou, A. Gason, S. Metcalfe, Ma Aitken, A. Bankier, and Mb Delatycki. "Evaluation of a Multi-disease Carrier Screening Programme in Ashkenazi Jewish High Schools." *Clinical Genetics* 78.1 (2010): 21-31.
3. Lavin, Norman. "An Introduction to Jewish Genetic Diseases: Part I | Jewish Diseases | Jewish Journal." *Jewish Journal: Jewish News, Events, Los Angeles*. 24 Jan. 2011. 08 Jan. 2012.
<http://www.jewishjournal.com/jewish_diseases/item/an_introduction_to_jewish_genetic_diseases_part_i_20110124/>.
4. Remennick, Larissa. "The Quest for the Perfect Baby: Why Do Israeli Women Seek Prenatal Genetic Testing?" *Sociology of Health & Illness* 28.1 (2006): 21-53.
5. Wailoo, Keith, and Stephen Gregory. Pemberton. *The Troubled Dream of Genetic Medicine: Ethnicity and Innovation in Tay-Sachs, Cystic Fibrosis, and Sickle Cell Disease*. Baltimore: Johns Hopkins UP, 2006. Print.

Appendix:

- a. Sample interview questions
- b. Letter of introduction (Note: the letter will be catered to those participating in the June mass genetic screening and previous mass genetic screenings in Chicago, as well as those who have expressed interest in participating in Kansas City)
- c. Email correspondence with the Chicago Center for Jewish Genetic Disorders, several patients in the Kansas City area, and Michael Begleiter

Interview questions:

Orthodox, conservative, reform and mixed-marriage Jewish patients

1. Background demographic information: gender, age, religious affiliation, education level, occupation, brief personal and family history of Ashkenazi Jewish genetic disorders
2. From whom or what resource did you receive information on screening/ testing?
3. What was your motivation to pursue or forego testing at such time? How did you decide on this particular method of testing over other options?
4. Did you have any hesitations and/ or concerns prior to screening?
5. Did you fully understand the screening results and the resources/ options offered? How did you proceed with results (i.e. sharing results, testing other family members, etc.)
6. Did your perception of screening/ counseling change through the process? If so, how has your perspective changed over time?
7. Do you believe awareness is a problem? How, if at all, have you joined the outreach effort to promote awareness? If not, do you propose any ideas to improve prevention?
8. Are you familiar with Dor Yeshorim? If so, what are your feelings regarding Dor Yeshorim?
 - a. Should a young person inquire about the carrier status of a potential spouse on a social level before or after meeting?
 - b. Should two carriers break up an engagement or refuse to marry?
 - c. Must a known carrier divulge their carrier status to their significant other or intended spouse?
 - d. Is it acceptable to hope for the best, arrange an abortion, or have an affected child?
9. Describe your overall satisfaction with the process. What additional services, changes or improvements would be beneficial?
10. Is there anything else you'd like to share about the experience?

Physicians and genetic counselors:

1. Discuss your goals, as well as the challenges that arise regarding your educational, awareness and prevention efforts.
2. How can educational efforts maximize testing without arousing excessive levels of anxiety?
3. Describe the challenges that arise during the screening/ counseling process.
4. Do you adapt the process to individuals of varying Jewish denominations, and if so, how?
5. What is the optimal time for education and screening?
6. What are the pitfalls of carrier screening (i.e. inconclusive or insensitive results, variable expressivity, misinterpretation of results, genetic discrimination, confidentiality)? How do you address and propose to improve these barriers?
7. Who and when should it be decided to pursue testing?
8. Should and what are the limits to pre-implantation, pre-natal and neonatal screening?
9. Who is entitled to screening results and how should genetic information be used?
10. What are your feelings regarding Dor Yeshorim?

- a. Should a young person inquire about the carrier status of a potential spouse on a social level before or after meeting?
- b. Should two carriers break up an engagement or refuse to marry?
- c. Must a known carrier divulge their carrier status to their significant other or intended spouse?
- d. Is it acceptable to hope for the best, arrange an abortion, or have an affected child?

Rabbis and religious leaders:

- 1. If and how was genetic screening/ counseling incorporated into your education, either in rabbinical school or current continued education?
- 2. How do you personally or do others on staff within your congregation play a role in the education or awareness efforts of Jewish genetic diseases?
- 3. What would be helpful to you to increase education within your congregation?
- 4. When is the optimal timing for screening and how could the Jewish community promote this cause (i.e. Hebrew school, Sunday school, young adult programming, etc.)
- 5. What are your feelings regarding Dor Yeshorim?
 - a. Should a young person inquire about the carrier status of a potential spouse on a social level before or after meeting?
 - b. Should two carriers break up an engagement or refuse to marry?
 - c. Must a known carrier divulge their carrier status to their significant other or intended spouse?
 - d. Is it acceptable to hope for the best, arrange an abortion, or have an affected child?

Letter of introduction:

Jewish Genetic Screening:

Evaluation of the barriers and strategies to increase education and awareness for young Jewish adults

I, Rachel Myers, am a first year medical student at the University of Kansas School of Medicine. The Clendening Fellowship Program through the Department of History and Philosophy at the University of Kansas Medical Center offers summer research fellowships for 8-10 first-year medical students to study an area of interest during the summer between the first and second years of medical school under the direction of one of the Department's faculty members.

As a member of the conservative Jewish community with career interests in endocrinology and preventative health, I have chosen to explore Jewish genetic diseases in greater detail, focusing particularly on the means of education, awareness and prevention in the varying Jewish denominations. I plan to conduct research largely by interviewing genetic counselors, physicians, non-profit agencies, religious figures and individuals undergoing carrier screening in both the Kansas City and Chicago area. I also plan to spend time at the Chicago Center of Jewish Genetic Disorders evaluating current means of education and prevention. Finally, I hope to organize a project of my own aimed at increasing awareness and education on college campuses.

Overall, the project will benefit the greater Jewish community by assessing how education and prevention efforts can be received with more enthusiasm. In addition to identifying methods through which awareness can be improved, the research will benefit patients participating in screening by assessing optimal timing and level of knowledge. The findings can also be applied to other clinics and non-profit agencies in promoting awareness.

Participation in the interview is completely voluntary and individual responses will remain confidential. Participation may be withdrawn at any time. After collecting and analyzing responses, results will be documented in a research paper and presented in a Clendening presentation in fall 2012. Feel free to contact me at your convenience with any questions and/or concerns via email

[\(name@kumc.edu\)](mailto:(name@kumc.edu)) or phone (000-000-0000).

Regards,

Rachel Myers

*"For being human holds a special grief
Of privacy within the universe
That yearns and waits to be retouched
By someone who can take away
The memory of death"*
-Epic of Gilgamesh, interpretation by Herbert Mason

Introduction:

My project focusing on end of life care has three facets: shadowing, research, and service. The goal of my project is to actively experience how hospice and palliative care providers use interdisciplinary care to meet the many needs of patients and families at one of the most important times of their lives. I will also administer an informal survey which focuses on the different ways nurses, physicians, chaplains, and social workers communicate with the patient. The data from the survey will be used to compile some simple pointers and guidelines that medical students could use in end-of-life care of future patients or eventually in counseling of patients about a serious diagnosis. Finally, I will compile a list of different services (wound care, EMR, incontinence services, 24-hour triage, etc.) offered by hospice centers in the Wichita area.

Background:

I have always had a knack for story-listening—not story telling. I am a lousy story teller, but there are few things in life that I enjoy more than sitting down with a friend, relative, or even a complete stranger and hearing her talk about her life, her experiences, her day. The wealth of experiences lived by each person and the kaleidoscope of views through which different people see those experiences have always enchanted me. For this reason, when I volunteered to serve lunch and assist the residents of the Catholic Care Center retirement community during the summer after my senior year in high school, I was in heaven! Some days, I received a comprehensive history lesson on World War II. Other days I was enthralled with detailed family genealogies traced as far back as the landing of the Mayflower. Hundreds of cherished family stories were entrusted to me and thousands of photos of grandchildren were placed lovingly in my hands. There is an undeniable wisdom, no matter how simply expressed, which prevails among those of a ripe, elderly age.

I found this same brand of wisdom again three years later when I worked at Camp Sanguinity, a summer camp for children on active treatment for cancer. Children always have stories to tell, but the stories told by these children were different. These stories sounded old and wise like those I had been privileged to listen to at the Catholic Care Center. I remember Shelby's (pseudonym) stories most. Shelby, like many of the kids at Camp Sanguinity, did not have hair, but she had such amazing blue-green eyes that they did not at all seem to be lacking a frame of eyelashes and eyebrows. They smiled along with her whole face when she laughed. There was also a depth in her eyes that showed evidence of pain and suffering beyond her years; however, I was surprised to find no fear in her eyes despite her dire diagnosis. The reason Shelby had no fear became clear to me as I listened to her stories.

She spoke of her cancer as a blessing. It had brought her family closer together. Before her diagnosis her parents had been arguing all the time and struggling to stay together, but the

fight for her health had once again united them in a single purpose. It brought out the best in her friends and classmates. Teasing and ridicule that she used to receive had been replaced by kind gestures and support that made her feel supremely loved and cherished. Finally, she said, it gave her the opportunity to come to camp each summer and experience things that she might not otherwise have been able to do: horseback riding, rockwall climbing, ziplining, and archery among her favorites. I was challenged by her outlook. Somehow, this thirteen year old girl was making me feel childish and foolish in comparison. Shelby passed away just a few months after telling me her stories and I have always felt incredibly blessed to have heard them.

There seems to be an invaluable wealth of wisdom in those nearing the dusk of their life. Those passing from this life seem to come to terms with death in ways as diverse as the lives they lead. I have had only limited exposure to people at the end of life and no exposure to the palliative care or hospice care environment. I am, however, drawn to the idea that each day of a person's life is valuable and should be enjoyed and cherished, not as a stepping stone to the next day or week or year, but simply for itself, in all of its wonderful 24 hours. I feel this is the focus and the goal of palliative care and hospice care medicine: to truly celebrate and honor a life when it becomes evident that it will end soon. I would love the opportunity to be able to learn and then share with my colleagues how best to aid these amazing patients in enjoying their time to tell the last of their stories.

Description:

I will be performing a primarily experiential learning project in palliative care and hospice medicine in Kansas City and Newton. Care for patients who are dying is a challenge faced by nearly all doctors. It is so universal that the *American Association of Medical Colleges* specifies that medical colleges need to produce compassionate and empathetic doctors who "care for people who are dying, even when disease-specific therapy is no longer available or desirable" (AAMC Report 2008). Research has shown that demonstration of empathy and compassion in end of life care leads to increased patient satisfaction, a reduction in negative symptoms, greater patient compliance, and reduced patient anxiety. Unfortunately, the evidence also "continues to show that in many institutions, [education for end of life care] remains at best ill-timed and often substandard or nonexistent" (Janssen 2010). I hope to help alleviate this gap in training by personally observing end-of-life care in a variety of environments, administering a survey to help elucidate elements of patient communication that are important for successful end-of-life care, and bringing my experiences and knowledge back to my peers and colleagues.

I have organized shadowing in three different palliative care or hospice care environments in Kansas City and the Wichita area. I will be working with Dr. Donna Ewy in the palliative care unit at the Via Christi Newton Clinic. Dr. Ewy is the medical director for Hospice Care of Kansas and family practice and palliative care doctor at the Via Christi Newton Clinic. I will be shadowing Dr. Ewy, the advanced registered nurse practitioner, and the chaplain in Newton as they care for palliative care patients. I will also be shadowing Dr. Ewy as she makes her rounds to 12 area nursing homes for palliative care work. I will also be shadowing Dr. Lindy Landzaat, an associate professor of internal medicine and palliative care doctor at KU hospital, while she is on palliative care service. Finally, I will be shadowing Dr. Ann Allegre and her staff at the Kansas City Hospice House. Dr. Allegre is the director of medical programs for Kansas City Hospice House, an unique care center which focuses on creating a home-like environment for patients and their families when care for the very ill or terminally ill becomes overwhelming.

As part of my shadowing experience, I would like to administer an informal survey (attached) to care providers willing to participate. It is designed to provide guidance for medical students on how to communicate with patients at the end of life. It will draw upon the knowledge and experience of many different types of care providers, including chaplains, physicians, nurses, and social workers. I have discussed this survey with Dr. Landzaat, Dr. Ewy, and Dr. Allegre.

I have also been in contact with Dr. Jerry Old, chief medical officer for Hospice Care of Kansas. He suggested that I might integrate a service aspect into my project by working to compile a reference sheet that contains all of the services offered by Wichita area hospice care centers to be used in area emergency rooms. A student on a hospice care internship a few years ago made a similar list for the Kansas City area, which is now widely used. Dr. Old thought it might be helpful for the Wichita area to have a reference sheet as well. Throughout the summer, I will be collecting information on which services are offered by Wichita area hospice care centers via phone surveys. I will then compile this information into a concise reference sheet that can be administered to area emergency rooms for quick referral reference.

Timeline		
Dates	Project	Purpose
May 21-25, June 2-3	Shadowing with Dr. Landzaat at KU Hospital on palliative care service	-- Experience palliative care in a hospital environment --Administer/collect provider survey
May 26-June 17	Shadowing with Dr. Ewy and staff at the Newton Via Christi Clinic on palliative care service	--Experience palliative care in a small-town clinic\ --Administer/collect provider survey --Compile hospice care reference sheet via phone surveys of Wichita area hospice centers
June 18-22	Shadowing with Dr. Landzaat and KU Hospital on palliative care service	--Experience palliative care in a hospital environment --Administer/collect provider survey
June 23-July 15	Shadowing with Dr. Ewy and staff at the Newton Via Christi Clinic on palliative care service	--Experience palliative care in a small-town clinic' --Administer/collect provider survey --Finish collecting information for hospice care reference sheet
July 16-July 27	Shadow Dr. Ann Allegre and staff at Kansas City Hospice House	--Experience palliative care in a family-supportive hospice house environment --Administer/collect provider survey

Methods:

I contacted Dr. Lindy Landzaat, an internal medicine and palliative care doctor at KU Hospital, to shadow for those time periods which she will be on palliative care service (May 21-25, June 2-3, 18-22). After filling out the appropriate paperwork, I will be able to shadow her at KU, and administer the optional survey to healthcare providers such as nurses, chaplains, social workers, and physicians during my time on service with her.

I have also contacted Dr. Donna Ewy, a family medicine and palliative care doctor at the Via Christi Clinic in Newton, Kansas. Although she spends quite a portion of her time in family practice, I will shadow her during the time that she will be on service for palliative care. The rest of the time I will spend shadowing the ARNP and chaplain on the palliative care unit at Via Christi clinic. The advantage of shadowing different healthcare providers is being able to observe

the different methods of communication used by different providers as well as the unique role which each person on the interdisciplinary team plays in the care of each patient. I will again administer the survey to the healthcare providers at this site. During whatever free time I may have or on the weekends, I will be working to compile a list of services offered by hospice care centers in the Wichita and surrounding areas using phone surveys.

Finally, I have scheduled a shadowing experience with Dr. Ann Allegre and her staff at the Kansas City Hospice House. In this unique environment resembling a home with the medical security that a hospital provides, Dr. Allegre suggested that I spend some time again shadowing with different care providers in an effort to really observe the communication that takes place between various caregivers and the end of life patient. I will again administer the survey to those caregivers willing to participate at KC Hospice House.

I have attached the pertinent email communications with Dr. Lindy Landzaat and Dr. Donna Ewy approving my shadowing experience with each of them. I have also attached the email communications with Kansas City Hospice House, although the final approval confirming me to work from July 16-27 was given during a phone conversation with Dr. Ann Allegre on Thursday, February 9th. I will be receiving the necessary paperwork within the next couple of weeks via email.

Dr. Jerry Old, a family practitioner and hospice and palliative care doctor in Lenexa, will be my contact for guidance on how to most efficiently and completely compile the list of services offered by hospice care centers in Wichita.

During my time in Kansas City, I will stay in my apartment at Rainbow Ridge. While I shadow in Newton, I will stay with my parents in Wichita.

I will be contacting the KU Human Subjects Committee to determine if I will need to apply for IRB exempt status in order to administer the survey.

Budget:

Budget	
Apartment Rent (June and July)	\$1250
Utilities	\$300
Food/Living Expenses	\$400
Gas and Transportation (Wichita, Newton, Hutchinson)	\$300
Total	\$2250

"Gaston exhausted every word he knew in Japanese to comfort Tsukada. He came to Tsukada's room every day after that and held the dying man's hands between his own palms, talked to him and encouraged him. Kiguchi could not tell whether such comfort eased Tsukada's pain. But the figure of Gaston kneeling beside his bed looked like a bent nail, and the bent nail struggled to become one with the contortions of Tsukada's mind, and to suffer along with Tsukada.

Two days, later, Tsukada died. His face was more at peace than anyone had imagined it could be, but a look of peace always comes at last to the dying...Kiguchi could not help but feel that this peaceful death-mask had been made possible because Gaston had soaked up all the anguish in Tsukada's heart."

--from "The Case of Kiguchi" in *Deep River* by Shisaku Endo

Bibliography:

Association of American Medical Colleges Report 1. (2008). Learning Objectives for Medical School Education: Guidelines for Medical Schools.
https://services.aamc.org/Publications/showfile.cfm?file¼version87.pdf&prd_id¼198&prv_id¼4239&pdf_id¼487

Janssen, A. & R. McLeod. What does care mean? Perceptions of people approaching the end of life. *Palliative and Supportive Care*. Vol. 8, p. 433–440, 2010.

Palliative Medicine and Hospice Caregiver Survey

What type of caregiver are you?

___Nurse ___Physician ___Chaplain ___Social Worker ___Other_____

Please rate your opinion	Strongly disagree	Disagree	No Opinion	Agree	Strongly Agree
Physical contact with the patient is essential to good end-of-life care					
I routinely speak with my patients about more than just their medical care					
I speak more with the family of the patient than the patient					
I seek opportunities to discuss death with patients					
I avoid discussing death with patients					
The patients seek opportunities to discuss death with me					
The patients avoid opportunities to discuss death with me					
I look forward to spending time with the patients					
Most of the patients are at peace with their own mortality					
End-of-life care is depressing					
End-of-life care is uplifting					

What is your favorite aspect of working with patients at the end of life?

What is the most challenging aspect of working with patients at the end of life?

Do you have any stories or experiences about working in end-of-life care that have really stayed with you that you would like to share?

Can you offer any guidance to medical students who have very little experience communicating with the critically ill or the dying?

Introduction

Alcohol abuse is the leading cause of liver disease in Western countries, and an estimated 50% of the population above 18 years-old in the United States drinks alcohol. There are three overlapping liver diseases that can result from alcohol use: hepatic steatosis, alcoholic hepatitis, and cirrhosis [1]. Hepatic steatosis may or may not be a precursor to alcoholic hepatitis, but regardless of the presence of steatosis, both extreme exposures to alcohol and/or prolonged, high-dose exposures put individuals at a greater risk for developing alcoholic hepatitis [1]. Patients with severe acute alcoholic hepatitis have a 20-25% chance of dying despite traditional treatment with corticosteroids and/or tumor necrosis factor alpha (TNF- α) antagonists, and have a 40% chance of dying within six-months of diagnosis [2]. Liver transplantation would be a definitive treatment for these patients, however, a shortage of organs, the concern of recidivism without the standard six-month period of alcohol abstinence, and insufficient research data on outcomes of transplantation in these patients, has made alcoholic hepatitis a contraindication of transplantation at most institutions [3].

Although data on early transplantation (done without a defined abstinence period) is currently inadequate, some prospective studies have shown that patients who receive early transplantation have significantly higher rates of survival up to two years post-transplantation compared to patients who do not receive transplantations [2,4].

Despite these promising data, many programs are still reluctant to begin doing this type of transplantation. One concern of doing early transplantation in patients with acute alcoholic hepatitis is a potential negative public reaction to doing transplantations in patients with active alcohol abuse and/or patients whose dedication to caring for their new liver turns out to be less than adequate. For example, if a donated organ is given to a patient who was initially thought to be unlikely to relapse into alcohol abuse, but subsequently dies due to continued alcohol abuse, potential organ donors may be reluctant to donate if they think their organs could be distributed irresponsibly.

The goal of this project is to explore the reaction of both healthcare professionals and the public to early transplantation in patients with acute alcoholic hepatitis, which will aid in future clinical decisions and provide a foundation for additional research on the topic of public response to changes in transplantation indications.

Background

Acute alcoholic hepatitis is a disease caused by prolonged, excessive drinking, and is thought to be a precursor to cirrhosis [5]. Alcohol itself is a hepatotoxin which also has toxic metabolites. These metabolites generate endotoxins, inhibit fatty acid oxidation, and initiate pro-inflammatory cascades which trigger hepatocyte necrosis or apoptosis [5]. Traditionally, the treatment for this condition has been corticosteroids and/or TNF- α antagonists, but as mentioned above, a significant number of patients who develop acute alcoholic hepatitis do not respond to pharmacologic therapy [2]. In 2007, there were approximately 57,000 hospital admissions in the United States for alcoholic hepatitis, for which there was a mortality rate of 6%. Thus, the number of these patients in need of early liver transplantation is a relatively small sub-set of patients within the category of liver disease secondary to alcohol damage [17]. An additional, new therapy that has been introduced in recent years is the Molecular Adsorbent Recirculating System (MARS), which is used to remove protein-bound toxins in the blood using dialysis

through an albumin-impregnated membrane [6]. However, data on this treatment are insufficient and more research on this technique must be done.

If these initial treatments are ineffective, as is the case in 20-25% of severe cases [2], patients do not have a good prognosis. Cases lie on a spectrum that range from mild to severe, but estimates of mortality in severe cases range from >50% in 30 days to 40% in six months [5,2].

The short time frame in which transplantation is possible has been a primary reason why these patients have not been considered for transplantation in the past because a minimum six-month abstinence from alcohol and counseling is generally required prior to transplantation by most programs [3]. The abstinence period is mandated as a way to make sure the patient can successfully commit to refraining from further alcohol intake and is dedicated to caring for the donated organ. Interestingly, a review of the literature evaluating the six month abstinence rule came to the conclusion that the six month period of abstinence was only one of several important factors in reducing post-transplant recidivism rates, such as family support, economic stability, and counseling [8]. Additionally, a recent prospective study of 167 patients who underwent liver transplantation for alcoholic liver disease of varying lengths of sobriety showed that abstinence length was a significant predictor of recidivism, and that with each month of abstinence there was a lower risk of recidivism [7]. However, almost half of the patients in that study had consumed alcohol post-transplantation and almost one quarter of the patients had engaged in harmful alcohol consumption. Importantly, the researchers noted that long-term studies of alcohol sobriety indicate that stable sobriety is achieved after about 5 years of abstinence [7], and they suggest that counseling and a supportive social network are more important than a few additional months of sobriety. Thus, these results do not suggest that abstinence length prior to transplantation is unimportant, rather, they suggest that a minimum of six months may not be necessary.

Currently, early transplantation in patients with acute alcoholic hepatitis is in its infancy, so the data on outcomes is lacking. However, in a study comparing patients receiving transplants with alcoholic cirrhosis alone and those with acute alcoholic hepatitis did not find significant differences between the two groups regarding survival or recidivism [9]. Importantly, abstinence periods for some patients were less than six-months and pre-transplant abstinence was not found to be a predictor of recidivism nor graft-survival [9]. Even stronger data comes from a study that examined patients who had clinically severe acute alcoholic hepatitis (Maddrey Discriminant Function of >32)ⁱ [10]. All of the patients in this study had abstinence periods of less than two months, and the three year post-transplant survival rate was 78% and recidivism rates were similar to patients receiving transplantation for alcoholic cirrhosis with a six-months abstinence [10,11]. Additional research has also found similar survival and recidivism rates between patients with acute alcoholic hepatitis and those with alcoholic liver disease without acute hepatitis [14]. One prospective study followed 18 patients who received liver transplants after an average of 9 days after being diagnosed as non-responsive to therapy. These patients were compared to 18 matched patients who did not receive transplant, and 1-year survival rates of transplanted were significantly higher (83% vs 44%), with over half of the non-transplanted patients dying within the first two months of being non-responsive to therapy [15]. Importantly, only one of the transplanted patients returned to drinking after 2.5 years [15].

Although the available data shows that transplantation for patients with acute alcoholic hepatitis is promising in regards to outcome and recidivism rates, implementation of early transplantation

has not been widespread. Although there are multiple reasons for this, one contributing factor is the concern of a negative reaction from potential organ donors. This study hopes to shed light on these concerns and allow transplant teams to make informed decisions regarding this issue.

Subject Selection Criteria

Subject selection is divided into two groups. The first group of subjects will be selected based on their affiliation with the Midwest Transplant Network and Gift of Life organizations. Healthcare professionals from the Midwest Transplant Network and members of the Gift of Lifeⁱⁱ will be selected to receive the survey.

The second group of subjects will be selected through the Amazon Mechanical Turk. A request for the survey will be made available to all members of the Amazon Mechanical Turk who are United States citizens.

Methods and Measurement Tools

This project will be carried out by distributing online surveys to physicians, nurses, transplant coordinators, and members of the general public. The survey will be created on and distributed through the KUMC Vovici Survey Workbench Enterprise and on the Amazon Mechanical Turk interface (AMT).

The survey will begin with introductory information on the topic of liver transplantation and early liver transplantation in patients with acute alcoholic hepatitis. Respondents will be asked to indicate their specific level of involvement in the healthcare field and/or transplantation. The respondents will then be asked to provide some demographic information including age, gender, race/ethnicity, and the state in which they were raised. They will then be asked if they plan to be an organ donor, and if so, what actions have they taken to do so. The self-reported level of alcohol intake will then be evaluated, and a question regarding their history of DUI's will be used as an indirect marker for prior alcohol abuse. Respondents will also be asked if they think there are any circumstances in which a person should receive a liver transplant for a liver disease secondary to alcohol.

The respondents will then be presented with a series of case vignettes describing a patient who develops acute alcoholic hepatitis who does not respond to pharmacologic therapy and will die without a liver transplant. The hypothetical patients will vary based on age, gender, level of family/social support, and socioeconomic status (ability to pay). With each vignette, the respondents will be asked to rate how they would feel about that patient getting a liver transplant without undergoing a six-month period of abstinence on a scale from 1-10 (1=very upset, 10=very happy).

At the end of survey, the respondents will be asked if news of transplantation in one of these patients would cause them to not want to donate their organs, and if so, to indicate which case(s). Respondents will also have an opportunity to rate how important they perceive age, family/social support, and socioeconomic status are when considering when to do early liver transplantation. Additionally, there will be a question asking if doing transplantations of this sort would change their perception of transplantation programs, and if so, how. After completion of the survey, there will be a thank you message with a short debriefing message assuring them that their responses are anonymous.

For more details on the survey, please see a copy of the survey accompanying this proposal.

The survey will be delivered to patients electronically either via email or using Amazon's Mechanical Turk. The respondents contacted via e-mail will be obtained through Dr. Forster's contacts at the aforementioned transplantation centers and organizations.

The AMT is a well-known method of distributing surveys online and is widely used in behavioral research to easily gain access to large, diverse populations of people [16]. The AMT works by providing the survey taker a small payment for completion of the survey. The survey will be launched with a finite amount of money in an account, and once the account runs out of money, the survey will be automatically deactivated. Respondents will be paid only after the survey quality has been verified. In order to verify the quality of the survey, one additional question will be inserted into the survey requiring respondents to read the entire question and mark a specific, pre-determined answer. This is recommended for use with the AMT because there are some people who are only interested in completing as many surveys as they can to make money; they do not read the surveys, but, rather, mark down random answers to complete the surveys as quickly as possible. This additional question will be the only difference between the surveys distributed on Vovici and AMT.

Statistical Analyses

Statistical analyses will be done using Microsoft XLSTAT Pro statistical software. Data will be expressed as mean \pm standard error of the mean. The reactions of physicians, other healthcare professionals, and the general public for the different cases will be compared, as well as reactions among cases within each group. Statistical significance will be determined by two-way repeated measures analysis of variance (ANOVA).

Significance

Organ shortages are a constant concern of physicians in transplant medicine, and, therefore, actions that could affect organ donation are of great concern. However, these physicians also want to provide definitive care to patients who will benefit from it and are also able to responsibly care for themselves after transplantation. The results from this study will provide an initial understanding of whether the reaction to an implementation of early transplantation for acute alcoholic hepatitis would result in backlash from potential organ donors. Transplant programs considering the acceptance of acute alcoholic hepatitis as an indication for transplantation (early transplantation), will find this data useful in their decision making process. In addition to contributing to information used for clinical judgments, this research will also provide initial data in a previously unstudied area. Because no other research has been done concerning public reaction to early transplantation for patients with acute alcoholic hepatitis, this study will be a source upon which additional research can be based.

Additional Experiences

In addition to this research component of this project, I plan to shadow Dr. Forster and his colleagues, in both the clinics and operating room to gain a better understanding of the process of liver transplantation from the perspectives of both physicians and patients, and also to better understand the ethical considerations that go into liver transplantations. I believe that these additional experiences will greatly add to my understanding of the ethical issues accompanying this topic, such as physician autonomy, a patient's right to the highest quality care, and utilitarian concerns of organ distribution and utilization of public funds.

Budget

Living Expenses -- \$850

Mechanical Turk Fees (500 respondents at \$2 per survey + 10% commission) -- \$1100

Microsoft XLSTAT Pro Student Upgrade -- \$50
Total -- \$2000

References

1. Crawford J. Liver and Biliary Tract. In: Kumar V, Abbas A, Fausto N, Aster J, eds. *Robbins and Cotran Pathologic Basis of Disease*. 8th ed. Philadelphia, PA: Saunders Elsevier; 2010.
2. Singal, AK. Liver transplantation in acute alcoholic hepatitis: Current status and future development. *World Journal of Hepatology*. August 2011; 3(8): 215-218.
3. Varma, V. Indications and Contraindications for Liver Transplantation. *International Journal of Hepatology*. Vol. 2011, Article ID 121862, 9 pages, 2011 (published online).
4. Mathurin, P. Early Transplantation for Severe Alcoholic Hepatitis. *New England Journal of Medicine*. November 2011; 365: 1790-1800.
5. Mailliard ME, Sorrell MF. Chapter 307. Alcoholic Liver Disease. In: Longo DL, Fauci AS, Kasper DL, Hauser SL, Jameson JL, Loscalzo J, eds. *Harrison's Principles of Internal Medicine*. 18th ed. New York: McGraw-Hill; 2012.
<http://www.accessmedicine.com.proxy.kumc.edu:2048/content.aspx?aID=9134918>.
6. Williams, R. The Influence of Alcoholic Liver Disease in Hepatology. *Alcohol & Alcoholism*. April 2008; 43 (4): 393-397.
7. DiMartini, A. Alcohol Consumption Patterns and Predictors of Use Following Liver Transplantation for Alcoholic Liver Disease. *Liver Transplantation*. March 2006; 12 (5): 813-820.
8. McCallum, S. Liver Transplantation for Alcoholic Liver Disease: A Systematic Review of Psychosocial Selection Criteria. *Alcohol & Alcoholism*. April 2006; 41(4): 358-363.
9. Wells, J. The Impact of Acute Alcoholic Hepatitis in the Explanted Recipient Liver on Outcome After Liver Transplantation. *Liver Transplantation*. July 2007; 13:1728-1735.
10. Shakil, A. Survival and Quality of Life After Liver Transplantation for Acute Alcoholic Hepatitis. *Liver Transplantation and Surgery*. May 1997; 3 (3): 240-244.
11. Hartl J. Strong predictor for alcohol recidivism after liver transplantation: Non-acceptance of the alcohol problem and abstinence of <3 months. *Scandinavian Journal of Gastroenterology*. October 2011; 46: 1257-1266.
12. Akriviadis, E. Pentoxifylline improves short-term survival in severe acute alcoholic hepatitis: a double-blind, placebo-controlled trial. *Gastroenterology*. December 2000; 119 (6): 1637-48.
13. Carithers, R. Alcoholic Liver Disease. In: Feldman M, Friedman L, and Brandt , eds. *Sleisenger and Fordtran's Gastrointestinal and Liver Disease*. 9th edition. Philadelphia, PA: Saunders Elsevier; 2010.
14. Tome, S. Influence of superimposed alcoholic hepatitis on the outcome of liver transplantation for end-stage alcoholic liver disease. *Journal of Hepatology*. June 2002; 36: 793-798.

15. Castel, H. Early transplantation improves survival of non-responders to steroids in severe alcoholic hepatitis: a challenge to the 6 month rule of abstinence. *Hepatology*. 2009; 50 Suppl 4: 307A.
16. Mason, W. Conducting behavioral research on Amazon's Mechanical Turk. *Behavioral Research Methods*. June 2011. (online publish prior to print)
17. Liangpunsakul, S. Characteristics and Mortality of Hospitalized Alcoholic Hepatitis Patients in the United States. *Journal of Clinical Gastroenterology*. September 2011, 45 (8): 714-719.

ⁱ Maddrey Discriminant Function is an index of liver damage that measures the patients total serum bilirubin and a comparison of the patient's prothrombin time (pt) to normal pt time (ptc). The formula used is $(4.6 \times pt - ptc) + \text{serum bilirubin} \left(\frac{mg}{dL} \right)$. A Maddre Discriminant Function great than 32 has been used as a marker of severe alcoholic hepatitis [10, 12].

ⁱⁱ The Gift of Life is a non-profit organization based in Overland Park, KS. Their mission is to build awareness of the need for organ and tissue donation, and to provide assistance to transplant patients, their families, and living donors.

Exploration of the Objective Diagnosis, Treatment and Prevention of Child Abuse and Neglect
Clendening Summer Fellowship Proposal
Paul Teran KUSOM 2015
February 13, 2012

Introduction

For the 2012 Clendening Summer Fellowship, I propose a project that will explore the objective diagnosis, treatment and prevention of child abuse and neglect. There will be three main focuses as I learn more about how physicians can confront child abuse. First, this project will include a review of pertinent medical literature, laws regulating medical professionals, and best practices for first responders to child neglect and abuse. Second, I will observe Dr. James D. Anderst in his daily clinic and rotations at Children's Mercy Hospital. Dr. Anderst is a Board Certified Child Abuse and Neglect Pediatrician at Children's Mercy Hospital, and he has made the commitment to serve as my mentor for this fellowship. Third, I will participate in research with Dr. Anderst to establish criterion validity of an assessment tool used to objectively diagnose levels of neglect. The compilation of these three efforts will provide me with a thorough knowledge of how physicians play a role in diagnosing, treating and preventing child abuse. The information gathered over the course of this fellowship will be presented in a report for the Clendening Summer Fellowship and the research I participate in will be continued to completion in hopes to make an impact on the objective diagnosis of child abuse and neglect.

Background

Before medical school, I had several jobs working with all ages of children. I have worked with high-school athletes at a summer sports camp, incarcerated teens at a detention center and with urban elementary aged children at an after-school program in Kansas City, MO. By working closely with children of all ages and socioeconomic statuses, I learned that child abuse is more prevalent than most people realize. I have developed a deep compassion for victims of child abuse and a personal commitment to learn about meaningful ways that I can respond to these needs.

My wife shares the same determination to help children in horrible situations. This past year we have explored the idea of becoming foster parents with the hope of being able to someday provide a safe, caring and loving home to children in need of care. We have decided that at this point, our lives are too hectic to provide a child with the care and attention they need. Still, we know that our commitment to this endeavor is solid and we plan to one day be foster parents and help children heal from trauma, like that experienced with abuse.

As a future physician, I will have a skill-set and a platform to be a first-responder and advocate for abused children. I do not know what kind of residency or specialty I will pursue, but I know that the skills I learn from working with Dr. Anderst will be valuable in equipping me to respond and care for needs of patients who have experienced abuse.

The Child Abuse and Neglect specialty is a dynamic new direction that the medical profession is embracing. It became a board certified specialty in 2010 after 216 physicians sat for the first board examination in the field in 2009 (Archer). The state of Kansas is also restructuring its child protective services department and policies in hopes to increase the efficiency and effectiveness. This July the Department of Social and Rehabilitation Services and the Department of Health and Environment will merge into the Kansas Department for Children and Families (Kansas). During this decisive time in the field of Child Abuse and Neglect, I believe it would be a valuable learning opportunity to experience a physician's role in recognizing and responding to the crime of child abuse.

I was quick to contact Dr. Anderst when I learned of his specialty and practice at Children's Mercy Hospital. Meeting with him, I gained a greater appreciation of his work and the personal challenges it presents. I was intrigued when he regarded child abuse as a preventable disease. He described to me about the different aspects of prevention, diagnosis and treatment that he is involved in and showed enthusiasm and support for my interest in the area and my commitment to learn more about the subspecialty this summer.

I chose the CSF because of the flexibility that it provides me. I want to explore the clinical aspect of treat child abuse victims. This includes diagnosing and treating child abuse as well as related issues that involve the law, the role of physicians in court proceedings, prevention efforts, parenting seminars and the long-term treatment needs of victims. My involvement in ongoing research in this field will be a contribution to understanding and responding to this significant societal problem not only for me personally but for the medical field as a whole. The combination of clinical experiences and research will expose me to the Child Abuse and Neglect Pediatrics specialty and provide knowledge and skills that I use in my career as a physician and an advocate for patients in my future care.

Description

Dr. Anderst and I decided that a combined clinical and research experience would maximize the knowledge and skills that I can gain from this project. In order to prepare for this experience, I will research Kansas and Missouri policies on the subject and read medical literature on the topic of child abuse and neglect. I plan to gain knowledge of diagnostic techniques and tools and a general knowledge of best practices for physicians confronted with victims of child abuse.

The clinical aspect of my CSF project will involve a variety of experiences. The SCAN Clinic (Sections on Child Abuse and Neglect) at CMH includes four Child Abuse Pediatricians, six Nurse Practitioners as well as social workers and a research coordinator. "The Section aims to advance the evaluation of potentially abused children locally, regionally, and nationally, by fostering excellence in clinical care, research, education, and investigation" (Children's). I will spend time shadowing the physicians in the clinic and on rounds in the hospital. I will learn about the procedures to diagnose abuse and neglect and the steps taken once a diagnosis is made. I will observe as the physicians work to care for the patients and treat all aspects of the injury.

Child Abuse and Neglect physicians are involved in the investigation of abuse cases. I will have the chance to follow Dr. Anderst as he formulates reports and works with the justice system to objectively determine if child abuse were present in a case. This experience will allow me to learn about the differing and collaborating roles of law enforcement, social agencies and physicians. The SCAN clinic is also active in our community with efforts to prevent child abuse and I plan to participate in programs and workshops offered locally to teach parents/caregivers how to properly care for their child and strengthen their relationship with their child (Children's).

All of the aspects of my clinical experience briefly described above will give me insight into how physicians can actively help children who have been abused. In order to formulate an all-encompassing experience, I will also take ownership of a research project for Dr. Anderst. The title is Criterion Validity of the RASS (Rapid Assessment of Supervision Scale). The RASS is a nine question tool designed to increase the objectivity in the assessment of supervisory neglect. It is still in development and I will be validating the efficiency of the RASS so that it can be used in practice. The hope is that physicians, social workers and child protective services workers will be able to use the RASS to quantify the amount of supervision a child had during an injury. This summer I will take responsibility for this research project and continue it until completion. This will involve distribution of the RASS to potential end-users, data collection, statistical analysis, and the formulation of a formal report.

Timeline

February-May	Finalize forms needed to work at Children's Mercy Hospital
May 11	End of Academic Year
May 14-June 3	Research state and federal policies and tools that are relevant to treating child abuse and neglect in Kansas City
June 4-July 27	Work with Dr. Anderst at CMH in SCAN clinic Execute RASS Criterion Validity research project
July 28- August 3	Gather information gained from all aspects of summer experience and formulate a Clendening report.
August 6	Start of Academic Year

Methods

Government policies and community resources pertaining to child abuse and neglect will be obtained from government and organization websites and communicating with local social workers. Medical Literature concerning child abuse and neglect will be reviewed from online databases provided by Dykes Library at KUMC. The collection of data will be an introduction to the field of child abuse and neglect to prepare me to spend the summer with specialists in the field.

I will begin my clinical experience by becoming familiar with the main aspects of the SCAN clinic and then diversify my experience by observing physicians on rounds, working with attorneys and law enforcement and as the physicians take part in preventative programs and workshops. Due to the serious nature of the issues related to my chosen topic, many of the examinations are video recorded for use in the justice system and procedures must be followed precisely. This means that most of my clinical time will be spent observing. However, I will actively participate in the clinical scenarios in which I am allowed. I am in contact with the Medical Student Coordinator at CMH and have begun filling out forms required for my time spent at CMH.

The research project will be a case-control retrospective review to determine the criterion validity of the RASS. A modified Delphi technique was previously used to create the contents of the RASS. The RASS has previously been tested to assess for agreement in the assessment adequacy of supervision in episodes of supervision from actual case data. The end-users in this testing were blinded to the child's actual injury status. Moderate to good agreement was found.

In order to establish criterion validity of the RASS, the injury status must be unblinded. I will present potential end-users with the RASS and actual case data from a collection of past cases (including child's injury statistics). The end-users include physicians, hospital/clinic social workers, and child protective services workers. They will fill out the RASS for each case. A higher score on the RASS indicates poorer supervision. The completed assessments will be collected and I will statistically evaluate the data. Associations of injury status with mean score (continuous variable) on the RASS and category of supervision adequacy (categorical variable) will be assessed with the Pearson correlation coefficient and the chi-squared test, respectively. Our hypothesis is that both higher mean scores and higher categories of supervision adequacy (indicating poorer supervision) will be associated with child injuries (Anderst).

I will continue the research to completion and present the data collected in a formal report. Although I have no significant previous research experience, I will be taking full responsibility for the execution and completion of this project. I will come across obstacles and have questions. Dr. Anderst and his research coordinator will work with me throughout the summer and help me develop a foundation of abilities to begin a life time of clinical research.

I plan to start the research aspect of this experience strongly at the beginning. I will start the summer with about 20 hours each week dedicated to research, and about 20 hours spent in clinic with the physicians. Over the course of the summer I will gauge the demands of the research in hopes to spend more time each week in clinic. I am excited for this amazing opportunity to be mentored by an expert, learn about the intriguing subspecialty and to gain skills that I will use the rest of my life. This will be a valuable learning experience for me that will propel me further into a lifetime of being an advocate for abused children.

Contacts:

James Anderst MD, MSCI Section Chief, Section on Child Abuse and Neglect Children's Mercy Hospitals and Clinics Associate Professor of Pediatrics UMKC School of Medicine	Kristen Moore Graduate Medical Education: Medical Student Coordinator Children's Mercy Hospitals and Clinics
---	---

Budget

Housing/Utilities:	\$400 x 3 months	= \$1200
Food:	Estimated \$500 for 12 weeks of summer	= \$500
Gas:	Estimated \$80 for CSF related transportation in KC	= \$80
Miscellaneous:	Research materials, printer ink and unexpected needs	= \$50
Total:		= \$1830

Thank you for considering my proposal for a 2012 Clendening Summer Fellowship.

Bibliography

Anderst, Dr. James D. Interview. Paul Teran. 16 December 2011.

Archer, Kim. Doctor certification to aid child abuse detection. 18 February 2010. 8 February 2012
<http://www.tulsaworld.com/news/article.aspx?subjectid=11&articleid=20100218_17_A1_DrsDeb588908>.

Children's Mercy Hospitals & Clinics. Child Abuse Pediatrics. 2012. 7 February 2012
<<http://www.childrensmercy.org/content/view.aspx?id=12906>>.

Kansas Department of Social and Rehabilitation Services. Social and Rehabilitation Services History.
2012. 8 February 2012 <<http://www.srs.ks.gov/agency/Pages/history.aspx#present>>.

Appendix B

FIGURE 1 RASS and Instructions for Use.

Instructions: Please rate each component individually, but in the context of all the other components. For example, the risk due to an individual child's age/development can only be determined in the context of other components, such as proximity of supervising caregiver and inherent dangers of the child's environment. A pot of boiling water sitting on the ground poses a higher risk to a mobile toddler than an immobile infant. The ratings for these components are interdependent, but must be rated individually.

- 0) No risk- component provides no risk of injury to the child
- 1) Minimal risk- component provides only minimal risk of injury to the child
- 2) Possible risk –component raises the possibility that injury to the child may occur
- 3) Moderate risk- component strongly suggests risk of injury to the child
- 4) High risk- component indicates significant risk of injury to the child

<u>Component</u>	<u>No Risk</u>	<u>Minimal Risk</u>	<u>Possible Risk</u>	<u>Moderate Risk</u>	<u>High Risk</u>	<u>Not Available/Applicable</u>	
Child's Age	0	1	2	3	4	NA	
Child's Development/ Maturity/ Skill Level	0	1	2	3	4	NA	
Physical, Mental, and Emotional Capabilities of the Caregiver	0	1	2	3	4	NA	
Responsibilities Given to the Child Were Age Appropriate	0	1	2	3	4	NA	
Level of Supervisory Attention Paid to the Child (visual, auditory, neither)	0	1	2	3	4	NA	
Proximity of Supervising Caregiver (Touching, Within Reach, Beyond Reach)	0	1	2	3	4	NA	
Continuity of Supervision Provided by the Caregiver (Constant or Intermittent)	0	1	2	3	4	NA	
Length of Time Child Unsupervised	0	1	2	3	4	NA	
Inherent Dangers in the Child's Environment (swimming pools, animals, stairs, etc.)	0	1	2	3	4	NA	
Total Score							
Mean Score							

Overall Classification of adequacy of supervision

- ☐ No Risk (0)
- ☐ Minimal Risk (1)
- ☐ Possible Risk (2)
- ☐ Moderate Risk (3)
- ☐ High Risk (4)

Notes

Primary Care in Tanzania



A Clendening Summer Fellowship Proposal

Christina Tippy

SOM 2015

February 13, 2012

Background:

I'll never forget the first day I walked into the hospital, squeezing through the crowd of people waiting for a first-come, first-served appointment. I proceeded to the clinic which consisted of two rooms, each housing a non-functioning sink, a well-worn exam bed, and a scantily stocked medicine cabinet. The hospital had no running water and the admitted patients were sometimes two to one sheetless bed and fifteen to a room. The hospital's pharmacy stocked vitamins, acetaminophen, penicillin, and not much more. Yet the rotating physicians I met were eager to work with what they had.

Before I arrived in Honduras in 2008, my history was a string of international and national stints of various types of volunteer work. I spent the first three months there taking intensive Spanish classes and teaching preschoolers at rainy season school, comparable to our summer school. As rainy season ended I found a volunteer position at a small pediatric clinic, which needed an intern, so I went to a tropical island thirty miles off the coast of Honduras. There I spent my mornings with rotating American pediatricians in a public Honduran hospital. I was inspired by my second week, and I started volunteering at another clinic on the island. The experience led me to go back to school and so I moved back to the states the following semester to pursue medicine.

As I consider how I will use my medical education, my heart is split between Kansas, near my family, and my passion for serving those most in need. The compromise, I believe, will be serving half time domestic and half time international medicine in developing countries. What I would like to accomplish this summer is to gain a better understanding of the role of a primary care physician in a developing country. I hope that gaining a better understanding of the challenges facing a family medicine physician in a developing country now, will provide me with a different perspective as I continue my medical education. I hope that this new perspective will allow me to grow into a better and more prepared physician in international medicine.

Description:

The average patient in Tanzania will initially present to a traditional healer, or if they can afford medication they will bypass any consultation and go straight to a pharmacy, where physical prescriptions are not necessary. If the illness persists, then the patient will seek out a provider. Primary care is usually provided by a clinical officer, a position comparable to a nurse. The clinical officer could then refer a patient on to a hospital to see a specialist, as there are not many primary care physicians.

The hierarchy of healthcare facilities in Tanzania are, from smallest to largest, dispensary, to a health center, district hospital, regional hospital, consultant hospital. Family medicine is a new specialty, which has only been offered as a residency option within the last few years. The consultant hospitals are the teaching hospitals in the large cities. I understand there are only four in the country. Each region in Tanzania has a regional hospital, and there are 26 regions. This means that each of these hospitals serves over a million people, some more than two million, and is mainly staffed by general doctors and surgeons who can refer to the consultant hospitals. A district hospital may have a couple of doctors a health center one doctor, and a dispensary is generally staffed by a medical assistant.

I will base my stay out of the hospital in Mwandege, where Dr. Joel Carpenter has offered to host me. I plan to visit a facility representative of each of these hospitals and centers to see all levels of the Tanzanian healthcare system. I plan to tour the facilities and interview physicians and some patients. I will also travel with Dr. Joel to rural villages where he travels monthly to do outreach clinics. I will go to the Centers for Disease Control and Prevention (CDC) with Deborah Carpenter to see and better understand the health issues of Tanzania. I am also still working on contacts to meet a traditional healer and a midwife as well.

My goal of this experience is to gather information by delving into a community in a developing country to see how primary healthcare is provided and received. This information will help guide my future experiences in my medical education, with the hope that I will be better prepared to practice in developing countries when I emerge as a physician.

Methods:

I plan to conduct interviews with physicians at each level of facilities. My main topics of interest are the funding of the facility, the non-monetary resources (i.e. medicine, safe water, etc.), the major needs and challenges of the facility and the community, the services provided by the facility, and the prevalent diseases. My main topics of interest with the patients are their experiences with primary care and how they access healthcare.

Luckily, Swahili and English are the national languages of Tanzania. Therefore, I should be able to conduct most of the interviews with physicians without the aid of a translator. There will be patients that speak only their tribal language, or only Swahili. The questions will be translated into Swahili. I plan on learning basic Swahili, although I do not feel it will be at a level I am comfortable with translating. I am prepared to employ a translator if necessary for interviewing patients.

I have included interview questions that I have drafted. If my proposal is accepted I will work with the Institutional Review Board to compile a final draft of interview questions.

I plan to video and photograph as much as I can and I hope to compile a 30 minute video upon completion which exemplifies primary care in Tanzania. A Kenyan friend, and native Swahili speaker, has agreed to help me translate and subtitle the video, where necessary.

Logistics:

I met Dr. Joel when he gave a presentation August 2011 at KCUMB (Kansas City University of Medicine and Biosciences). Doctors Joel and Deborah Carpenter have offered to host me at their mission base in Mwandege, Tanzania, which is approximately one hour south of Dar es Salaam.

I plan to arrive in Dar es Salaam on May 23rd where Dr. Joel will pick me up and I will travel to Mwandege. I will be staying at the established mission base at a cost of \$15 per day for room and board. I will primarily be traveling with Dr. Joel and his wife, Deborah who works for the Center for Disease Control. From there I will take daytrips to towns and cities to visit other hospitals where they have agreed to arrange visits for me. I plan on leaving Tanzania July 16th, then I will spend two week in

my hometown, Hays, Kansas, where I will compile the images and edit the video into my goal of having a half hour video of the experience.

This is a total of 10 weeks. I plan on taking two weeks off project in Tanzania to see some of the national parks, at my personal expense. I will be working on my Clendening project 8 weeks total.

Budget:

Plane ticket (Kansas City – Dar es Salaam)	1613
Room and board (\$15/day)	945
Additional in country travel expenses/translator	200
Photo and video	0
Total	\$2758
Out of pocket	\$258

I understand that expenses above and beyond the \$2500 Clendening scholarship will be paid for out of my pocket, and I have the necessary funds to compensate for the difference. The photo and video will be done using my own personal equipment. My brother has video editing resources (computers and software) and has agreed to assist and allow me to use his resources at no charge.

Contacts:

Drs Joel & Deborah Carpenter
Address: YWAM-TZ
PO Box 11401 Dar es Salaam, Tanzania

Interview questions for physicians/healthcare providers

What is the first point of care for the patients in this community?

Nini hitaji muhimu kwa mgonjwa wa jamii hili?

What preventative services does your facility offer?

Nini kingo linalotolewa na yenu?

What curative services does your facility offer?

Ni tiba gani mnalotoa katika ufasaha yenu?

What are the most common diseases you treat at this facility?

Ni magonjwa kani ambayo ya tibiwa katika ufasaha yen?

Why did you choose to go into healthcare?

Kwani uliamua kufanya somo la afia?

What is your educational background?

Nataka kujua uliosoma kwa shule?

What is your experience background?

Umarifa wa kazi yako?

What do you think could make healthcare better in your community?

Nini unafikiria litafanya afia uwewa hali ya juu

Interview questions for patients

What is the first place you go to address a health concern?

Ni wapi utaenda kueleza watu humuimu ya afia?

Have you ever been to a traditional healer? If so, what do you like most and least about traditional healers?

Umewai kwenda kwa daktari ya kienyeji? Ikiwa ume enda ni nini uliopenda sana na haukupenda sana kuhuzu daktari huyo?

Have you ever been to a hospital? If so, what did you like most and least about physicians?

Umewai kuwa katika hospitali? Ikiwa umewai, ni nini uliopenda sana na haukupenda sana kuhuzu daktari?

Where do you get most of your information regarding your health?

Unapata wapi habari kuhuzu afia yako?

What do you think are the biggest health problems in your community?

Unafikiri ni shida kani kubwa ya afia katika jamii yako

Why do you think we have these problems?

Kwani unafikiri huko na shida hili?

What do you think should be done to make your community healthier?

Unafikiri nini litafanywa hili jamii yako liwe na afia?