

Clendening Summer Fellows, 2010 Directory

Name	Title	Pages
Lindsay Allan	"Observing Health Risk behaviors in Kansas City's Homeless Teens"	2 - 8
Hilda Audardottir-Goulay	"How WHO is Expanding Access to Health Literature"	9 - 16
Neil Bryan	"Without 911: Access to Acute Medical Care in Belize"	17 - 24
Elizabeth Cathcart-Rake	"Quality of Life for Students of Different Abilities in Lima, Peru"	25 - 32
Katie Grelinger	"Patterns of Alcohol Consumption in Hungary"	33 - 43
John Hunninghake	"Social Support Services for Oncology Patients in Kansas City"	44 - 55
Jenna Kennedy	"Observing Nutrition in Rural Guatemala"	56 - 62
Katie McAnany	"The Role of Faith among Pediatricians in Mexico"	63 - 68
Rehaan Shaffie	"Mobile Medicine and Barriers to Care"	69 - 76
Zahra Shirazy	"Heroin Addiction in Mombasa, Kenya"	77 - 88

The Efficacy of Educational Programming in Changing Health Attitudes and Behaviors in

Homeless Youth at Synergy House

Lindsay M. Allan

University of Kansas School of Medicine

Kansas City, KS 66103

Date Submitted: February 16, 2010

A Word from Dr. Tarris Rosell

Lindsay Allan's project is one that has emerged and been refined over the course of this first year in medical school. She has consulted with me numerous times, exhibiting a tenacious commitment to learning more about teenage homelessness, with a focus on health and healthcare. Her affiliation with Synergy House provides unique access to professional providers and their minor clients in a sheltered environment. Their typical thirty day stay, with structured interventional activities, offers a window of opportunity for developing trust relationships and measuring impact. Already Lindsay has identified probable gaps in knowledge that she could begin to address through a well thought out survey with analysis. I am particularly enthusiastic about the potential she has for hearing and documenting stories of homeless teens, with an ear especially to health narratives. Lindsay has shown herself to be one who listens empathically, thinks carefully, and writes articulately. I am supportive of her intent to apply for a Clendenning Fellowship, and will continue my mentoring support if her application is successful.

Introduction

It is difficult to spot the homeless youth in Kansas City. Unlike the adult population, they strive to blend in—wearing the clothing of kids their age and choosing not to panhandle. Though they may not sleep under bridges, two thousand of Kansas City's youth lack a fixed, regular, and adequate nighttime residence.¹ The homeless youth population is largely hidden from the public eye owing to its movement into and out of domiciles, public institutions, and the streets.² Specific to Kansas City, teens describe the lifestyle as "couchsurfing," which can range from staying with friends or friends-of-friends (sometimes at a very high cost to their personal well-being) to bouncing back and forth between shelters.³ Studies have shown that this migratory lifestyle has negative effects on the health and well-being of teens. Sexually transmitted infections are among the leading health problems of homeless adolescents, and rates of HIV infection are 2 to 10 times higher than in other domiciled adolescent populations.⁴ Also, injuries, dermatologic problems (including lice and scabies infestations), and malnutrition have been reported as important health problems for homeless teens.⁵ Recently, a lot of attention has been given to how homelessness affects the lives of youth in Kansas City. Just this month, the front page article in the Kansas City Star featured the Davis family, a working-class family from Raymore living in a motel because they fell behind on their utilities.⁶ They represent the 'new homeless' population created by the economic downturn in working-class America.⁶ Even Johnson County, the wealthiest county in Kansas,⁷ is not immune; it counted 227 homeless students in January and is considering adopting an enrollment policy on homeless children.⁶ On February 4th, KMBC 9 News reported that the number of homeless teenagers in Kansas City is growing because of stressful financial situations in homes; it also featured Synergy Services as the organization providing teenagers with a path out of homelessness. Synergy House, an entity run by Synergy Services, Inc., is a homeless youth campus that provides emergency shelter and support services for adolescents. Teenagers are allowed to live at Synergy House for up to thirty days, and while there, can receive mental health counseling, medical and dental care, life-skills training, and computer access.¹ They also have opportunities for leadership development and community service.¹

In 2007, 2008, and 2009, Synergy served 311, 352, and 344 youth respectively.^{8,9,10} In November 2009, Synergy House doubled their occupant space for youth from twelve to twenty-four, and now has the capacity to serve almost twice as many youth.¹ For any given year at Synergy, about forty percent of the youth under the age of 18 are homeless, and one hundred percent of the youth who are 18 are homeless.¹¹ Because Synergy House receives federal monies from The Runaway and Homeless Youth Act (RHYA), it serves homeless youth as defined by the legislation. As a Basic Center Grant Program (as defined in Part A of the legislation), Synergy House can provide services to youth seeking shelter who are no more than 18 years of age; for whom it is not possible to live in a safe environment with a relative; and who have no other safe alternative living arrangement.¹² The clientele data from Synergy House's annual report, for years 2007, 2008 and 2009, indicates that it served 149, 175, and 181 *homeless* youth respectively^{8,9,10}; it is significant to note that Synergy also receives private funding, allowing it to also serve youth that do not meet the RHYA's specific definition of homelessness. Though RHYA mandates that centers such as Synergy House provide safe and appropriate shelter and individual, family, and group counseling, it does not require any educational program geared towards improving the overall health of the youth.¹³ However, for the past three years, Synergy House has incorporated weekly nutrition groups, bi-monthly sex education sessions, frequent trips to the YMCA, and has utilized the Casey Life Skills Curriculum to enrich the learning experience of the youth at the shelter.^{8,9,10} The Casey Life Skills Curriculum is a free, online suite of tools which allow youth to assess their strengths in life skills such as career planning, housing and money management, and self-care.¹⁴ To remain at Synergy House, youth must follow five rules, one of which is to participate in the provided education sessions.⁹

I am the most interested in learning about the impact Synergy House has upon the health attitudes and behaviors of the youth. Homeless teens are clearly at a higher risk of having compromised health statuses, and the results from this research will elucidate the efficacy of the current educational programming at Synergy House. As a youth advocate at Synergy House, I have formed relationships with people within the agency who are knowledgeable about the homeless youth situation in Kansas City and are familiar with other organizations providing similar services. This feasibly allows for expansion of this project to other shelters in the city, thereby positively impacting more youth. Ultimately, the Clendening Summer Fellowship would provide me with the financial backing, and more importantly, the legitimacy to conduct this research in the context where it is the most relevant and needed.

Methods

The goal of this study is to determine the impact educational programs have on the health attitudes and behaviors of youth at Synergy House. A pre-Synergy survey will establish a baseline of the teenagers' knowledge and behavior. During admission to Synergy House, the youth must complete a brief orientation with a youth advocate, and they must also meet with their assigned case worker thereafter. Rachel Francis, the Youth Services Program Manager for Synergy House, suggested that either meeting would be a good opportunity to administer this pre-Synergy survey. At the end of their stay, a post-Synergy survey will be administered in order to determine what they have learned as a result of participating in Synergy House's educational programs. It will explore questions such as: Can

they identify high-risk behaviors? Will they apply the new information they have acquired to their lives? This survey will be administered during their discharge. (See appendix for example questions of pre- and post- Synergy surveys) A second post-Synergy survey will be administered thirty days after the first and will answer questions such as: Did they retain the information? Did they apply the information to their lives? This data will most likely be the most difficult to obtain because it will either require the youth to return to Synergy or to meet with me somewhere outside of Synergy. I would like to use a ten dollar coupon as an incentive for the youth to follow up with me. For this project, I will use the guidelines set forth by Healthy People 2010 as the physical and nutritional goals for the youth. Attitude or behavior changes bringing youth closer to these goals would be an indication of the effectiveness of the programming. This information will be obtained through analysis of the questionnaires.

Conclusion

I am eager to better understand the youth I serve, which will inevitably help them. I have been changed by the youth, whose trials haunt me and whose resiliency inspires me. My experience at Synergy House has given me the desire and the necessary connections I need to propose this summer research project, however, it will be the Clendening Summer Fellowship that will provide me with the freedom and the resources I need to make a difference in the lives of homeless youth in Kansas City.

Timeline

February to March: Finalize surveys and finish my application for the Institutional Review Board

April to July 15th: Work with case workers at Synergy House to administer surveys and gain data on the homeless youth.

Remainder of July: Analyze collected data.

Budget

One hundred, \$10 coupons as an incentive for the youth to come back in thirty days for the second post-Synergy survey.	\$1000
Gas for transportation over the summer: \$75 per month	\$225
Total	\$1225

Contacts

Rachel Francis
Youth Services Program Manager

Lara Sickel
Assistant Program Manager

Chas Marks
Street Outreach and SafePlace Coordinator

Tarris Rosell, PhD, DMin
Clinical Associate Professor (Ethics)
Dept of History & Philosophy of Medicine
KUMC, School of Medicine
Co-Chair, KU Hospital Ethics Committee

Works Cited

1. "Homeless youth campus." *Synergy Services*. Web. 14 Feb. 2010.
<http://www.synergyservices.org/?page=Main_Our_Services_Youth_Synergy_House>.
2. Ringwalt, Christopher L., Jody M. Greene, Majorie Robertson, and Melissa McPheeters. "The prevalence of homelessness among adolescents in the united states." *American Journal of Public Health* 88.9 (1998): 1325-329. *PsychINFO*. Web. 14 Feb. 2010.
3. "Interview with Chas Marks, Street Outreach and SafePlace Coordinator." Personal interview. 17 Dec. 2009.
4. Rotheram-Borus, Mary Jane, Cheryl Koopman, Clara Haignere, and Mark Davies. "Reducing HIV Sexual Risk Behaviors Among Runaway Adolescents." *The Journal of the American Medical Association* 266.9 (1991): 1237-241. *JAMA & Archives*. American Medical Association. Web. 14 Feb. 2010.
5. Ensign, Jo, and John Santelli. "Shelter-based homeless youth: Health and access to care." *Archives of Pediatrics & Adolescent Medicine* 151.8 (1997): 817-23. *PsychINFO*. Web. 14 Feb. 2010.
6. Bradley, Donald. "Tough Times Create the 'New Homeless'" *Kansas City Star* [Kansas City] 10 Feb. 2010, News sec.: A1. Print.
7. "ERS/USDA Data - KS Unemployment and Median Household Income." *USDA Economic Research Service - Home Page*. Web. 14 Feb. 2010.
<<http://www.ers.usda.gov/data/unemployment/RDList2.asp?ST=KS&SF=11D>>.
8. *Synergy House 2007 Annual Report*. Rep. Kansas City: Synergy Service, Inc, 2007. Print.
9. *Synergy House 2008 Annual Report*. Rep. Kansas City: Synergy Services, Inc, 2008. Print.

10. *Synergy House 2009 Annual Report*. Rep. Kansas City: Synergy Services, Inc, 2009. Print.
11. "Interview with Rachel Francis, Youth Services Program Manager for Synergy House."
Telephone interview. 15 Feb. 2010.
12. "The Runaway and Homeless Youth Act 2 (Title III of the 3 Juvenile Justice and Delinquency Prevention Act of 1974)." Administration for Children and Families. Web. 14 Feb. 2010.
<<http://www.acf.hhs.gov/programs/fysb/content/aboutfysb/RHYComp.pdf>>.
13. "The Runaway and Homeless Youth Act 2 (Title III of the 3 Juvenile Justice and Delinquency Prevention Act of 1974)." Administration for Children and Families. Web. 14 Feb. 2010.
<<http://www.acf.hhs.gov/programs/fysb/content/aboutfysb/RHYComp.pdf>>.
14. *Casey Life Skills*. Web. 14 Feb. 2010. <<http://www.caseylifeskills.org/index.htm>>.

Appendix

Pre-Synergy Survey

1. What is the recommended level of physical activity for youth your age? Does this reflect your level of activity?
2. How often do you exercise? What do you do when you exercise? How long do you exercise?
3. What are the food groups and how much of each should someone your age eat every day? Does this reflect your diet?
4. What do you eat (Please list the foods and quantities of a typical day)? How often do you eat?
5. Do you think you are a "healthy person"? (On a scale of 1 to 10, with 10 being the most healthy and 1 being very unhealthy).
6. Do you know how to get medical coverage for your healthcare?
7. How often do you see a physician?
8. How often do you see a dentist?
9. Do you know where your birth certificate is?
10. How many times have you been to the emergency room? What for?
11. Are you sexually active? What do you do to protect yourself against sexually transmitted infections? Do you use birth control?
12. When was the last time you had a pap-smear?
13. When was your last physical?
14. Why are you at Synergy?

Post-Synergy Survey

1. What is the recommended level of physical activity for youth your age?
2. What are the food groups and how much of each should someone your age eat every day?
3. Do you know how to get medical coverage for your healthcare?
4. Do you know where your birth certificate is?
5. How likely are you to wear a condom during sex?/ How likely are you to ask your partner to wear a condom before sex?
6. What do you think about birth control?
7. What does safe sex mean to you?
8. Has Synergy House impacted how you view your health?

Is HINARI Working?

Analyzing Usability and Efficiency of Access to Online

Medical and Biochemical Health Literature

A Proposal for the Summer 2010 Clendening Fellowship

By Hilda Audardottir-Goulay

KUSOM 2013

Introduction

Immediate access to thousands of medical journals is changing modern medicine. Where physicians once spent hours in a medical library poring over catalogs, journals, and textbooks, our medical school class received instruction on how to use PubMed to research a case during our orientation to medical school. Every time we gather in small groups, we use AccessMedicine and Harrison's Online to look at charts, recent data, and even established medical textbooks. This is truly an incredible resource; something I know will benefit our patients on a tangible clinical level. However, when one compares our experiences to those of students and even physicians across the globe, it becomes clear that we are the exception and not the rule.

In parts of the world where physicians perform surgeries without electricity, practice in clinics without running water, and work in offices without enough money for even sterile gloves, can we truly expect physicians to be up to date on latest research? If we believe that every human being has the right to the absolute best medical care available, must we not also state that physicians have the right to the latest information necessary to treat their patients? Through my recent travels and contacts, I have learned of a World Health Organization program called HINARI. The HINARI project of the WHO strives to meet the goal of increasing access to medical information by offering access to thousands of online medical and science journals. For physicians and researchers at institutions where the exorbitant subscription fees of most online journals and databases is simply too high, HINARI offers access to these priceless resources at a greatly reduced cost, or sometimes even for free.

Despite its seemingly clear advantages and lofty goals, is HINARI enough? Is the theoretical access to these databases really improving clinical care? For physicians and researchers who struggle to provide the best medical care possible in areas with so few resources, does it really matter to have access to online medical journals? Is the HINARI Program really effective? I am proposing a research project for the summer of 2010 to analyze HINARI user satisfaction to try to answer these questions.

Background

I have seen the importance of evidence-based medicine not only in the medical school curriculum here at KU, but also in practice in the Infectious Disease Clinic at Georgetown University Hospital, where I was in charge of organizing the biweekly Journal Club. Every two weeks, attending physicians, fellows, and residents would come together to discuss pertinent articles and case studies not more than two weeks old. They would find a case study similar to a particularly challenging case in clinic, or simply present new data on drug side effects of drugs used daily in the clinic. Each attendee had a copy of the latest information on every topic pertinent to the clinic, ensuring that the patients they would see that day would be receiving the most modern and effective medical care. Treatment options and medications can change from year to year if not month to month, and I have seen from both my work experience in a clinic and my time in medical school, that physicians must use all resources available to them when treating patients.

While traveling in the summer of 2009, I had the opportunity to have a tour of the WHO facilities in Geneva Switzerland. While touring the library, I learned about the HINARI program that works to bring access to these modern medical databases to institutions in countries with low GDPs. I returned to talk to Mr. Ian Roberts, the Library Coordinator for the WHO about HINARI. Mr. Roberts was able to tell me about the history and goals of HINARI, and it truly piqued my interest. If evidence-based medicine is becoming so essential to adequate patient care, should all physicians and researchers not have access to the best and most recent information? What is the point of publishing a paper on a new treatment plan for Tuberculosis if the physicians working in tuberculosis-endemic areas do not have access to the information? If all people have the right to the access to healthcare, should all physicians not have the right of access to the same resources?

The World Health Organization is the agency of the United Nations that is charged with coordinating international health activities and helping governments improve health services. As such, the WHO has a list of 6 goals that it hopes to promote. They are Promoting Development, Fostering Health Security, Strengthening Health Systems, Harnessing Research, Information, and Evidence, Enhancing partnerships, and Improving Performance ("The WHO Agenda").

In order to achieve its goals, the WHO establishes various programs and charges them with specific missions. HINARI is one of those programs. HINARI is the Health InterNetwork Access to Research Initiative. The WHO works with major publishers to allow researchers and physicians at institutions in developing countries to access collections of biochemical and health literature ("HINARI General Information"). Currently, HINARI allows access to over 3750 journal titles to institutions in 113 countries. The purpose of these resources is to aid health sector institutions in developing countries by providing high quality, timely, relevant biomedical and social science journals for free or very low prices ("HINARI General Information"). The price that institutions pay is based on the GDP of their country. Countries are considered Band 1 if their GDP is less than 1250USD per capita and Band 2 if their GDP is between 1250 and 3000 USD per capita. Band 1 countries receive free access to HINARI, starting in 2002. Band 2 countries must pay a fee to use HINARI, 1000USD per year per institution ("HINARI General Information"). The HINARI program has been approved by the WHO to continue through 2015, at which time it will be adapted as needed after review. What I hope to do is begin to understand how researchers and physicians use HINARI, and try to measure their satisfaction levels, and perhaps even collect some new ideas for adaptations to the program.

As I researched the HINARI program and others like it, I discovered the importance of analyzing the actual usage and efficacy of HINARI. The goals behind HINARI are lofty, but it is difficult to analyze whether the program is effective for physicians and researchers. Since the HINARI program is under official review in 2015, it is important to continually analyze how clinicians and researchers utilize the online journals in order to present a powerful argument for continuing the program, or perhaps even for changing it for the better. One potential problem is that researchers and physicians do not feel confident in using the internet to download medical articles (Ajuwon). For many people, the internet is still much of a novelty and is not yet a trusted resource as a book or magazine in the hands would be. Perhaps it is necessary for HINARI to advertise how doctors in advanced countries and wealthy institutions rely heavily on the internet for their information. Also, research in Peru has suggested that some of the journals expected to be accessible with the HINARI project were not actually found to be accessible (Villafuerte-Gálvez). At the same time that users suggested problems with HINARI journals, subscription to other online databases has increased, leading to the conclusion that perhaps the HINARI program is being weakened with less impact-heavy journals being available. This is a potential weakness in the program that I could further investigate and analyze to determine a solution that would lead to increased HINARI use. Another concern with HINARI is just general knowledge of the program. For those physicians who are interested in research and in using HINARI, do they know about the program and do they have easy access to the resources they should? In a study of four teaching hospitals in Africa, only 47% of physicians had heard of HINARI (Smith) and at some institutions physicians mentioned difficulty logging on to the HINARI system and even having passwords guarded by librarians (Smith). These are concerns that I would like to present to HINARI users to garner opinions about their experiences with the HINARI program to compile an overview of the current status of the HINARI program from the standpoint of its users.

I learned about HINARI less than a year ago, but I have become immensely interested in how this program could be helping more health care providers, researchers, and even government agents. As someone who truly believes in the democratization of information, I think that programs like HINARI are a valuable and meaningful resource, but that we must continue to analyze and adapt the programs to keep them user friendly and efficient. Thus, I would like the opportunity to research and analyze current

HINARI users in order to develop a report on current usage, potential problems, and most importantly, solutions and plans for the future.

Description

The overall purpose of my research project is to identify positive and negative aspects of the HINARI project in regards to ease of access, satisfaction with the resources provided, and overall clinic and research usefulness. HINARI represents an impressive investment for the WHO, and I hope to be able to present the HINARI managers with helpful information as to the development of this important program.

When I first decided that I would like to take complete a research project about HINARI, I contacted Ms. Kimberly Parker, the Program Director of HINARI for the WHO. I spoke to her about my interest, and she expressed an eagerness to allow me to work with her this summer. As this research project qualifies as an internship for the WHO, I will continue to work closely with Ms. Kimberly Parker before arriving in Geneva to develop a plan for the project. We have developed an initial timeline and framework as follows. We discussed that the first three to five days will be spent developing the questions that I will ask HINARI users. As we are working to develop the questions for the survey, I will also work to identify ten heavy-use institutions internationally. One of the factors I will need to consider is ease of contact with the HINARI users, as I will need to have direct contact with the users within a relatively short period of time. As I work to contact HINARI users at these heavy use institutions, I will work to develop the survey of questions to ask the users. I have included below some questions that Ms. Parker and I have developed:

- How often per week do users log on to the online medical journals provided by HINARI?
- How many papers have been published from your institution since you have joined the HINARI program?
- How many articles accessed through HINARI have been cited in the papers published from your institution?
- Has HINARI access affected the desire of physicians/researchers/user to publish more papers?
- Has HINARI access affected the desire of physicians/researchers/user to write more papers?
- Are users likely to access HINARI to use in the clinical setting as well as the research setting?
- How has HINARI access affected direct patient care?
- How would HINARI be more helpful to your users/researchers/physicians?

The current timeline for my project expects me to gather information for four weeks and analyze and prepare a report for two weeks. After gathering the surveys and information, I will prepare a report that identifies the ways in which actual users find that HINARI is helpful and ways that HINARI can be approved. Since this is a more subjective way of looking at HINARI usage, it will help to develop some new ideas for HINARI implementation. By presenting HINARI users with more open-ended questions, I am providing an outlet for communication in which users can have direct contact with the managers of the HINARI program. After analyzing user opinions about HINARI, I will prepare a concise report for the HINARI program managers that can be further researched and developed as the HINARI program progresses and works for more funding to continue in the coming years.

Methods

My project depends on my ability to identify and then contact institutions that use the HINARI program. This is why it is necessary that I work within the parameters of the WHO library. In the fall of 2009, I contacted Ian Roberts, the current Acting Coordinator for the WHO Libraries. He put me in touch

with Ms. Kimberly Parker, who is the Program Director for HINARI. I presented my idea to research the usefulness of the HINARI project and she agreed to take me on as an intern for the summer. The WHO stipulates that internships must run six weeks, and in order to accommodate Ms. Parker's schedule, we set the dates of the internship to run from May 24 2010 to July 2 2010.

Since HINARI is a project run by the WHO libraries, it is the libraries that keep vigilant track of HINARI user institutions. I will be able to use this information not only to gather information about HINARI users, but also to be able to contact the various users in order to conduct interviews. Contacting these users on my own would be a daunting task, but since I will be working on behalf of the WHO, HINARI users are expected to cooperate with the research project.

My interview questions will be developed by both myself and Ms. Parker in order to reflect not only my own research interests, but also the interests of the WHO in gathering information about the usability and efficiency of the HINARI project. I will have the support of the WHO library staff, as well as the guidance of Ms. Parker, the program's director. After conducting my interviews, I will have the support and resources of the WHO library in order to analyze my findings and put together my final report.

Professional Contacts

- Ms. Kimberly Parker- HINARI Programme Director, WHO
World Health Organization

I have been working very closely with Ms. Parker as I worked on this proposal, as I will only be able to complete the project with the use of WHO resources. As such, I have applied for an internship position through the WHO so that Ms. Parker will be able to work closely with me during the summer. Thus, I have included my email correspondence with Ms. Parker as "Appendix A". I hope that my correspondence with Ms. Parker illustrates that not only am I dedicated to pursuing this project, but I have put a great deal of effort into the planning process in order to ensure that this project will be a success.

- Mr. Ian Roberts- Acting Coordinator Library & Information Networks for Knowledge,
WHO World Health Organization

As the current coordinator of the WHO libraries, Mr. Roberts will be my main resource when I analyze my findings and complete my final report. Furthermore, Mr. Roberts has offered any resources possible as I form my survey questions and conduct interviews.

Living Logistics

My father lives and works in Geneva, Switzerland. I have had the opportunity to visit him multiple times and am therefore fairly familiar with the city. Living with my father will also greatly reduce my budget needs. Geneva has a very efficient bus system and I will be able to take the bus from my father's apartment to the WHO building every day.

Budget

Plane Ticket \$1146

Food Expenses \$15 /day for 2 months \$900

Bus fare 4CHF each working day for 6 weeks = 120CHF = \$100

Total Estimated Expense- \$2136

I understand that I will be responsible for any additional costs outside of the support provided by a Clendening Fellowship

Conclusion

I have an immense interest in International Health, and the HINARI program is a meaningful resource that I look forward to researching. This research project would not be possible without the resources of the Clendening Fellowship, and I am thankful for the opportunity to submit this proposal. Please do not hesitate to contact me for any further information.

Bibliography

- Ajuwon, Grace A. "Use of the Internet for health information by physicians for patient care in a teaching hospital in Ibadan, Nigeria." *Biomedical Digital Libraries* 3.12 (2006): n. pag. *PubMed*. Web. 3 Feb. 2010. <<http://www.bio-diglib.com/content/3/1/12>>.
- "HINARI General Information." *HINARI Access to Research*. World Health Organization, 2010. Web. 20 Jan. 2010. <http://www.who.int/hinari/faq/general_information/en/index.html>.
- Smith, Helen, et al. "Access to electronic health knowledge in five countries in Africa: a descriptive study." *BMC Health Services Research* 7.72 (2007): n. pag. *PubMed*. Web. 3 Feb. 2010. <<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1885254/?tool=pubmed>>.
- Villafuerte-Gálvez, Javier, Walter H Curioso, and Oscar Gayoso. "Biomedical Journals and Global Poverty: Is HINARI a Step Backwards?" *Public Library of Science* 4.6 (2007): n. pag. *PubMed*. Web. 3 Feb. 2010. <<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1896213/?tool=pubmed>>.
- "The WHO Agenda." *About the WHO*. World Health Organization, 2010. Web. 20 Jan. 2010. <<http://www.who.int/about/agenda/en/index.html>>.

Appendix A

Correspondance with Ms. Kimberly Parker



HINARI Internship

15 messages

Roberts, Ian Francis

Fri, Dec 11, 2009 at 3:52 AM

Hello Hilda,

Many thanks for your message and interest in an internship within our unit.

I do believe that there is 'space' for you to carry out work on specific evaluation/impact analysis of the HINARI programme. There are also many other projects relating to HINARI that might be of interest to you during your 2 months stay in Geneva. Therefore, I am also sending this reply to my colleague Kimberly Parker, HINARI Programme Manager. We have discussed and agreed on the possibilities for an interesting internship/study this summer. Kimberly will follow up and contact you rapidly as all internship applications for next summer are to be submitted before 31 January 2010.

When you have both set some draft/tentative dates and topics, please go through the internship description pages on WHO's website (<http://www.who.int/employment/internship/en/>) and specifically apply for an internship with "Information, Evidence and Research" Cluster - also mention that you wish to work within the Library and Information Networks for Knowledge on the HINARI programme.

Looking forward to seeing you soon!

With kind regards,
Ian

Ian Roberts
*Coordinator a.i.
Library & Information Networks for Knowledge
Department of Knowledge Management & Sharing*

Emergency Medicine in a developing nation

An evaluation of emergency medical systems in Belize, and comparison with a U.S. system



Neil Bryan

Summer 2010



Imagine you are at home with your sick child. She has had a mild fever throughout the day, and you have scheduled a doctor's visit tomorrow morning. Suddenly she has a seizure. Having taken a CPR course at the local Red Cross, you are able to determine that she has a pulse and is breathing. You use your cell phone to call 911, where a trained dispatcher gathers your information. Within 10 minutes an Advanced Life Support ambulance arrives, staffed by two Paramedics. They rapidly assess your child, administer oxygen, and give her IV medications to stop the seizure. They obtain a 12-lead EKG and start her on medications to help her low blood pressure. Should she require it, they can intubate her and support her breathing. Since you live in a rural area almost an hour's drive from a large hospital, the Paramedics called an EMS helicopter when they were dispatched. The helicopter lands in a field nearby and the flight crew meets with the ambulance crew.

After stabilizing her, the flight crew rapidly transports her to a large Emergency Room, where they are met by a board-certified Emergency Medicine physician and ER nurses. The ER staff has an arsenal of diagnostic and treatment options to treat your sick child: they perform a lumbar puncture to check for infection; utilize a CT scanner to check for any brain masses or bleeds; draw blood to have it analyzed for infection and fluid/electrolyte imbalances. Finally, your child is admitted to the hospital under the care of a Pediatric Critical Care physician. During your drive to the hospital, you are able to use your cell phone to check in with the ER staff on your child's condition. Happily, she makes a full recovery. Your insurance pays the tens of thousands of dollars of medical bills, with you responsible for only \$250—an easy sum for a dual-income family making more than \$70,000 a year.

Now imagine a slightly different scenario: same sick child, same fever. But there is no Red Cross CPR training in your village, and the only medical care you know is what has been handed down from parent to child. There are no phones in your village, no electricity. It is evening, and by candlelight you see your child seizing. You tell your eldest child to run to the river to get a bucket of water to cool your child's head; you have no running water. You wished that this month's government supply of medication for the village had included something for fever, but there was nothing.

The nearest paved road is 12 miles away; the nearest hospital another 60 miles, about a 2-hour drive over pothole-filled roads. But there is no vehicle in the village. Hopefully the plantation van will come in the morning to pick up the village's men to work in the banana fields—if there is work. You will see if they will drive you to the paved road, where you can wait for the public buses to come. With \$12 as your family's savings, it will be enough to buy you a ticket to the town, where you can walk a few miles to the hospital. Once you get there, you hope that they can help your baby. Your eldest child, 12, will have to watch over the other children, make tortillas, and tend to the chickens while you are gone. You have no idea when, or how, you will return.

This is the situation faced by millions of people in the world. In developing countries such as Belize access to emergency medicine can be limited by geography, communication, finances, cultural beliefs, and lack of general infrastructure. Ironically, those who are least able to access outside help are also those who have the fewest resources to deal with emergencies on their own: education, basic utilities, first aid/medical supplies, etc.

Belize is a developing country located on the eastern coast of northern Central America. It is unique in that, as a former British colony, English is the official language and it belongs to the Commonwealth of Nations. Its population is rich with a diverse heritage, including Mayan, Caribbean, Spanish, Scottish, and African ancestry. Belize is divided into seven districts, each responsible for the implementation and development of its own medical infrastructure, including hospital-based and pre-hospital Emergency Medical Services (EMS).

Much of the population lives below the poverty line, with banana and sugar cane plantations being the largest employers in the country. Small villages dot the landscape, many effectively isolated from the day-to-day workings of the country. The northern districts, with the influence of tourism, are richer and more highly developed, with larger cities and hospitals. The southern districts are more rural, with "Polyclinics" substituting for hospitals.

Interest

Prior to starting medical school, I worked in the medical field as a Flight Paramedic and EMS Educator. I spent 13 years providing pre-hospital and hospital-based emergency care, as well as teaching multiple disciplines such as ACLS, PALS, and PHTLS. I was also a Training Officer for EMS classes for the State of Kansas. I have a very strong interest in ensuring that the public has quality EMS, because I have seen the outcome of patients who either received poor care, care too late, or no care at all.

During Spring Break of 2009, I traveled with KUMC International Outreach to Belize, where we set up traveling clinics in small villages. During one of these clinics a mother brought in her infant son, who was septic. We ended up transporting him by van to a hospital; during the van ride he suffered a hypoxic seizure. Thankfully we were able to resuscitate him, and he eventually made a full recovery. It has stuck in my mind, though, what might have happened had we not been there that day. In the words of the treating doctor at the hospital, "Most babies this sick never make it here." That is what initially sparked my interest in returning and learning more about Belize and its medical system.

Description

My proposal is to travel to Belize during the summer of 2010 to learn about the country's emergency medical services and how various factors influence the public's ability to access such services. I will learn how emergency medical services are designed, implemented, and equipped from the medical community's viewpoint, and compare that with how emergency medicine is perceived, accessed, and funded by the public. In addition, I will work to gain first-hand knowledge of the way medical providers of various levels are educated. A fundamental focus will be to study how EMS has evolved to meet the specific demands of Belize.

I then will return to the United States and compare the Belizean responses with those of U.S. rural and mid-sized cities, focusing on recent immigrant populations.

The results of the surveys and interviews, as well as my journal, will then be used to prepare a presentation summarizing my findings.

Timeline:

May 22	Travel to Belize City, Belize.
May 23	Bus to Belmopan, Cayo District
May 24-June 4	Work in Western Regional Hospital, Belmopan
June 5-6	Tour Belmopan, prep for village travel
June 7	Village visit: Valley of Peace
June 8	Village visit: Yalbac
June 9	Village visit: San Ignacio
June 10	Village visit: San Antonio, Cayo District
June 11	Village visit: San Miguel Camp
June 12	Travel by bus to Independence, Stann Creek District
June 13	Tour Independence, meet with physician mentor
June 14-20	Work in Independence Hospital, Independence
June 21	Village visit: San Pedro
June 22	Village visit: Blue Creek
June 23	Village visit: San Vicente
June 24	Village visit: San Benito Poite
June 25	Village visit: Corazon
June 26-27	Punta Gorda: interviews
June 28	Bus to Hopkins
June 29	Village visit: Kendall
June 30	Village visit: Maya Center
July 1	Bus to Belize City
July 2	Fly to Kansas City
July 3	Drive to Joplin, MO

July 4 4th of July

July 5-11* Work in St John's Regional Medical Center, Joplin, MO

July 12-17* Work in McCune-Brooks Hospital, Carthage, MO

July 18 Return to Kansas City

* During these times I expect to work 3-4 shifts a week. During non-clinical days, I will be holding interviews with the public.

Methods

- I will spend 6 weeks in Belize. For four weeks I will work alongside a physician providing hospital-based emergency care: two weeks each in the cities of Belmopan and Independence (northern, larger city and southern, smaller city). I also will ride with the local EMS when available. Both provider and public interviews will be performed during this time. Printed surveys will be utilized when appropriate.
- I then also spend 2 weeks travelling to 10-12 smaller villages to talk with the public. This will be done utilizing village Health Workers and schoolteachers as points of contact, so as to both show respect for their roles and to facilitate open communication. This will provide a more complete view of the public's views: these populations may be the most underserved, and variances in geography and district economies will be important factors. I will contact villages in at least 3 different districts to account for such variances. A local guide/translator from Ya'xche Conservation Trust will be used for translating and cultural awareness.
- Returning to the U.S., I will work alongside a physician providing hospital-based emergency care for 2 weeks in Joplin and Carthage MO. I also will ride with the local EMS during this time.
- During these two weeks I will talk with the public during non-clinical days (3-4 days per week). I will utilize area churches and immigrant-focused aid organizations as points-of-contact for access to the public. Specifically, I focus on contacting immigrant/minority populations (Hispanic in Joplin, Vietnamese in Carthage).
- A journal will be maintained during the entire 8 weeks, documenting what types of medical emergencies were encountered, how the medical system handled such patients, and any other relevant observances. Personal experiences will also be documented. Although Belize does not have HIPPA, I will utilize this as a guideline in maintaining patient confidentiality in all surveys, journal entries, presentations, etc, both in Belize and the United States.

Sites of Study, Belize

- Western Health Region hospital, Belmopan
- Southern Health Region hospital, Independence
- 10-12 villages: 3-4 villages in each of the Cayo, Stann Creek, and Toledo Districts

Sites of Study, United States

- St John's Regional Medical Center, Joplin, MO
- McCune-Brooks Hospital, Carthage, MO
- 3-4 towns in Southwest Missouri

Contacts

- Belize
 - Western Regional Hospital, Belmopan: Director
 - Southern Region, Independence Hospital: Dr Bhupathi Raju, Acting Deputy of Regional Medicine
 - Village visits: Julio Chub, Ya'achxe Conservation Trust, Belize
- United States
 - St John's Regional Medical Center: Dr James Riscoe, MD
 - McCune-Brooks Hospital: Dr Micheal Eastman, DO
 - Joplin, MO: Matt Derfelt, Pastor, Journey Church
 - Carthage, MO: Congregation of the Mother Co-Redemptrix

Preparation

Confirm Belize village visit dates/locations and Belmopan hospital dates.

Finalize questionnaires and have them translated into Spanish, Vietnamese, and Kekchi (if possible).

Personal preparation will consist of a Spanish self-study program. I also will increase my Spanish utilization during patient contact at JayDoc.

Budget

Round-trip airfare KC to Belize City	\$900
Lodging in Belize (\$30 U.S./day)	\$1140
Food (\$15 U.S./day)	\$570
In-country travel (bus tickets, taxis, rental car)	\$550
Gifts for villages, total	\$80
Anti-malarial medication	\$70
Belize exit fee	\$40
Roundtrip gas cost to Joplin, MO	\$60
Lodging in Joplin (home stay planned)	Free
Travel expenses in Joplin/area (gas)	\$30
Food (\$20 U.S./day)	\$320
Printing costs (questionnaires)	\$10
Translating cost (questionnaires)	\$20
TOTAL:	\$3790

I understand that all expenses above and beyond the \$2000 Clendening scholarship will be paid for out of my pocket, and have savings put aside for same. I consider this a valuable investment in my education, both in life and as a future physician.

Sample interview questions: Public

1. What types of medical emergencies happen to people in your village/town?
2. What emergency medical care is available in your village/town?
3. Who provides emergency medical care in your area?
4. When would you seek medical care outside your village/town?
5. How do you access emergency medical care?
6. How would you rate the emergency medical services in your area?
7. What financial expenses are there to you if you seek emergency medical care?
8. What are the traditional ways of treating medical emergencies in your area? Are these still used?
9. If so, how do they compare with the way doctors/hospitals provide care?
10. What else about emergency medical care in your area, or in Belize, is important to know?

Sample questions: Medical providers

1. What is your role in emergency medicine?
2. Please describe the education typical for your role:
3. What types of medical cases do you typically see?
4. What patient demographics do you see?
5. What specialist care is available to your patients?
6. What concerns or barriers do people face when accessing emergency medical care? Are all people able to access emergency medical services?
7. What changes would you like to see in the way emergency medical care is structured or delivered?
8. What else about emergency medical care in your area, or in Belize, is important to know?

Introduction

This project will investigate quality of life outcomes at a school for children with different abilities, Centro Ann Sullivan del Peru (CASP), in Lima, Peru. The primary mission of CASP is to help students with different abilities (a term used by the center to emphasize these students' achievements rather than their limitations) lead happy, productive lives by improving the education of students and families and by emphasizing these students' unique achievements. In addition, an ophthalmologist often conducts vision interventions with the children at CASP, as many children with different abilities also have vision limitations. The investigator will develop and then utilize tools to analyze the individual and combined effects of the CASP educational program and vision interventions on the quality of life of students with different abilities and their families. The conclusions of this study will contribute to the understanding how CASP improves quality of life in children, the ophthalmology needs of the population, and the outcomes of the combination of vision interventions and the CASP program. Furthermore, the conclusions of this study can help inform other facilities for students with different abilities and help new locations open new, successful CASP facilities.

Background

My goals for this summer are to improve my Spanish, learn about a new culture, help those in need, and get clinical experience. As I began discussing these hopes with my family and members of my community, I learned about the Centro Ann Sullivan del Peru in Lima, Peru. I was particularly drawn to CASP and the vision clinics run for CASP students, because of the program's dedication to improving the lives of young people and their families who are so often

marginalized in society. I talked with Dr. Linda Lawrence, the ophthalmologist who conducts vision interventions for CASP students, and Dr. Liliana Mayo, the founder of CASP and also an adjunct professor of Applied Behavioral Science at the University of Kansas, about putting together a project that would match my goals and their needs. While CASP has witnessed positive changes in the lives of students with different abilities, it has not yet been able to quantify the effects of the school on student and family quality of life. Furthermore, there is a significant gap in the literature on the effects of vision interventions on quality of life among children with different abilities. Thus, Dr. Mayo and Dr. Lawrence asked that my research focus on investigating changes in quality of life among children with different abilities who have gone through CASP and/or a vision intervention.

In addition to conducting needed research, while working with CASP and the vision interventions, I will be able combine my two passions: medicine and psychology. The medical side of the project will be very informative, because this project will allow me to observe and participate in ophthalmology clinics. It will be an excellent chance for me to determine whether ophthalmology is a career path that I would like to pursue. Furthermore, I will spend two days at a children's hospital in Lima, and will observe many different aspects of children's medicine. The psychology side of this project, assessing quality of life by interviewing and statistics, will allow me to apply my background as a psychology major. I completed a psychology senior thesis in college and worked on a professors' research project involving coding interviews about quality of life, both of which have provided me with a solid foundation in research methods, interview techniques, and statistics. I am well prepared to create an interview, conduct an interview, code responses, and translate the qualitative data gained by an interview into

quantitative data. The research review board at CASP as well as Dr. Mayo and Dr. Lawrence will oversee the project.

This project will require Spanish fluency. While I have had 3 semesters of Spanish in college, in order to be better prepared for the Spanish aspect of my project, I will spend 4 weeks in immersion Spanish classes and a homestay in Antigua, Guatemala before flying to Lima, Peru. The Spanish school, Proyecto Linguistico Francisco Marroquin, was highly recommended by a family friend, and facilitates students staying in homestays. I will be checking the translations of the interview and interview questions with Dr. Mayo and Dr. Lawrence. In addition, I will have interpreters at CASP to help with the interviewing process as well as the translations.

Timeline and Method:

February - May: Kansas City

- Research past studies of quality of life with children with different abilities
 - o PubMed searches on quality of life, vision interventions, and multiple disabilities
 - o Contacts: Dr. Mayo and Dr. Lawrence
- Refine interview questions, create a tentative coding manual
 - o Contacts: Dr. Mayo and Dr. Lawrence
- Enroll in Spanish classes in Antigua with connected homestay
 - o Language School: Proyecto Linguistico Francisco Marroquin
 - o Contacts: info@languagelink.com, Emily Auerbach, prior student, www.langlink.com/Guatemala-general-info
- Book flights

June 6 - June 27: Antigua, Guatemala

- Take Spanish immersion classes 8 hours/day, live in homestay
 - o see contacts above
- Translate interview, consent forms into Spanish
 - o Contacts: Dr. Lawrence, Dr. Mayo

June 27 - July 26: Lima, Peru

- Live in homestay with person involved with CASP
 - o Contact: Dr. Mayo, CASP
- Interview 10 students and their families, teachers, and bosses, if applicable
- Spend 2 days at a children's hospital
- Spend 1 week in the Andes with Dr. Lawrence in vision clinics
 - o Contact: Dr. Lawrence

Description

The mission of the Centro Ann Sullivan del Peru (CASP) consists of three core elements: treating every student with dignity, using a functional/natural curriculum, and working in teams with the families so students may lead happy, productive lives. It is a nonprofit, nongovernmental organization in Lima, Peru where students are taught to reach individual goals based on their unique abilities in an accepting, nurturing environment. The functional/natural curriculum of CASP emphasizes the building of meaningful relationships between student and teacher and relies upon praise as a means of reinforcing positive behaviors. Many older students are successfully trained to work in their local communities and are thus able to achieve independence as well as contribute to their family's income. CASP is a strong force in families as well as the community, helping community members better understand, relate to, and accept people with different disabilities and their families. CASP is also a place in which health professionals can come and help to correct some students' physical barriers. For instance, Dr. Lawrence visits there often to correct vision problems, as many children with different abilities also have vision problems.

While CASP witnesses positive outcomes with children and families every day in the classroom, it has not yet quantitatively measured the programs' effects on the families. Furthermore, research on the outcomes of vision interventions in children with different abilities has not been found. My goal for my time in Peru will be to develop and begin to implement a qualitative and quantitative measurement of student outcomes from both the CASP program and the eye clinics. Dr. Lawrence, Dr. Mayo, and I will develop an interview for students, their families, teachers, and bosses (if applicable) that will ask about past and present quality of life, satisfaction with the program and the visual intervention, challenges still faced by students and

their families, resources needed to meet these challenges, and hopes for the future. This interview will allow CASP and medical professionals to determine the individual and combined contributions of vision interventions and the CASP program to improved quality of life in students with multiple disabilities and their families. I will then interview and document the lives of 10-15 (or more, if possible) students and families who have been involved in CASP and/or have had visual interventions. I will tape record the interviews and take photographs and short videos of the students' and the students' families' lives, transcribe the interviews, and develop initial conclusions. It is the hope of CASP and Dr. Lawrence that volunteers will continue these interviews and eventually collect enough data to publish a paper about the effects of CASP and visual interventions on the quality of life of students with multiple disabilities and their families.

The following questions will be addressed in this project:

How have vision interventions with students with multiple disabilities affected their abilities to complete tasks, communicate, and lead a more independent lifestyle?
How have vision interventions affected students' relationships with peers, family members, and the community?
How have vision interventions affected students' feelings of well-being and outlooks on life?
What resources are needed to further improve students' vision?
How has CASP affected the students' abilities to complete tasks, communicate, and lead a more independent lifestyle?
How has CASP affected students' relationships with peers, family members, and the community?
How has CASP affected students' feelings of well-being and outlooks on life?
What resources are needed to help CASP further improve students' abilities to lead happy, productive lives?

The following questions are possible interview questions for this project:

Notes: These questions are presented as if the researcher is interviewing the child, however in many cases, they will be modified to ask the parents if the child is unable to answer or feels more comfortable with the parent answering. More questions will be added to ask teachers and bosses. Furthermore, the questions will be improved and made more understandable for students in the upcoming months. The questions will be translated into Spanish.

Describe the tasks you were able to complete prior to CASP.
What kinds of tasks did you need help with prior to CASP?

How did you feel about yourself before you were enrolled in CASP?
 What was your relationship with your family like before CASP?
 What was your relationship with your peers like before CASP?
 What made you decide to enroll in CASP?
 What were your expectations of CASP before you enrolled?
 What kinds of things are you working on in CASP?
 What kinds of tasks are you able to complete now you have enrolled in CASP?
 How do you feel about yourself now that you have enrolled in CASP?
 What is your relationship with your family like now you have enrolled in CASP?
 What is your relationship with your peers like now that you have enrolled in CASP?
 What resources would you have liked CASP to have available?
 What kind of vision intervention did you have done?
 Describe the tasks you were able to complete prior to the visual intervention.
 What tasks did you need help with prior to the visual intervention?
 How did you feel about yourself before you underwent the visual intervention?
 What was your relationship with your family like before the vision intervention?
 What was your relationship with your peers like before the vision intervention?
 How did the vision intervention affect your vision?
 Describe the tasks you are able to complete after the visual intervention.
 What tasks do you need help with after the intervention?
 How do you currently feel about yourself?
 How has your relationship with your family changed after the vision intervention?
 How has your relationship with your peers changed after the vision intervention?
 What kinds of tasks do you wish you could accomplish?
 In what ways could your experience have been improved?

In addition to these interviews, I will be helping with one of Dr. Lawrence's short-term eye clinics in the Andes for one week while I am in Peru. While I will not be able to see the long-term changes on quality of life for the local population, I will be able to help assess ophthalmology needs and quality of life issues among people with different abilities in indigenous populations in Peru.

Budget:

Flight	Flight to Guatemala City (transportation to/from airport included in Spanish school budget), Flight to Lima, Flight back to MCI	\$ 1500
Spanish School	8 hours/day + homestay + 2 meals/day for 3 weeks in Antigua, Guatemala	\$ 933
Guatemala Food	1 meal/day in Guatemala	\$ 210
CASP fee	\$250/week CASP fee + \$70/week for	\$ 1110

	homestay w/ breakfast + \$50 total for lunches at CASP	
Week in the Andes	Living situation + meals + travel to the Andes	\$400
Dinner in Lima	Dinner 1 night/day for 3 weeks	\$ 200

Total = \$ 4353

I will also be applying for a grant from the Special Olympics to cover the remaining expenses. If I am unable to cover all of the trip expenses with scholarships and grants, I will use my student loans. I am also applying for IRB approval. This application is completed, except for an advisor's signature and then will be turned in promptly. I will send you the notification of receipt of my application when it arrives.

Bibliography:

Documentary about CASP online: www.justlikeanyone.com

Information about CASP online: www.annsullivanperu.org

Paper highlighting the educational philosophy of CASP:

Mayo, L., LeBlanc, J. M., and Oyama, R. (2008). An educational program developed to teach people with different abilities to be independent, productive, and happy, to show what they can do, and to be included in all activities in life as a valued member of society. Developed for: *Schiefelbusch Institute for Research in Life Span Studies, University of Kansas* and *Centro Ann Sullivan del Peru*.

Information about Proyecto Linguistico Francisco Marroquin: info@languagelink.com, www.langlink.com/Guatemala-general-info, Emily Auerbach, prior student

Phone conversations and meetings with Dr. Liliana Mayo, Director of CASP, and Dr. Linda Lawrence, ophthalmologist

Past research on the subject of vision interventions and quality of life for children with multiple disabilities:

Boulton, M., Haines, L., Smyth, D., and Fielder, A. (2006). Health-related quality of life of children with vision impairment or blindness. *Developmental Medicine & Child Neurology*, 48:8: 656-661.

Boulton M, Clegg S, McDonald E, Fielder R. (2004) Quality of life of children with a vision impairment and their parents. *Quality of Life Research* 13(9): 1577.

De Civita, M., Regier, D., Alamgir, A., Anis, A., Fitzgerald, M., and Marra, C. Evaluating health-related quality-of-life studies in paediatric populations: some conceptual, methodological and developmental considerations and recent applications. *Pharmacoeconomics*, 23(7): 659-85.

- Scott, I., Smiddy, W., Schiffman, J., Feuer, W., Pappas, C. (1999). Quality of life of low-vision patients and the impact of low-vision services. *American Journal of Ophthalmology*, 128(1): 54-62.
- Stelmack, J. (2001). Quality of life of low-vision patients and outcomes of low-vision rehabilitation. *Optometry and Vision Science*, 78(5): 335-42.
- Wolffsohn, J.S. (2000). Design of the low vision quality-of-life questionnaire (LVQOL) and measuring the outcome of low-vision rehabilitation. *American Journal of Ophthalmology*, 130(6): 793-802.

The Hungarian Perspective on the Rise and Sustained Level of High Alcohol Consumption

A Clendening Summer Fellowship Proposal By Katie Grelinger

February 16, 2010

Introduction:

Hungary has recently become infamous for having a widespread high level of alcohol consumption. From wine, including their own famous Tokaji, to the locally distilled hard liquor, pálinka, it is impossible to go anywhere without being offered a drink and rarely, if ever, just one. Excessive drinking is noted by the World Health Organization as a major health problem of the nation, and in 2000, the mortality due to alcohol-related problems was over three times the European Union average in men and around two and a half times that of average EU women ("Health in Hungary," Country Cooperation Strategy). A full 10% of the population has been officially diagnosed with alcoholism, saying nothing of those who have not been diagnosed (Bereczki). This, however, has not always been the case. Between the 1950s and the 1980s, alcohol use in Hungary increased markedly from a per capita consumption of 4.9 liters/year to numbers ranging from 11.7 to nearly 17, coinciding with the Soviet Union's communist regime in the country (Skog and Elekes 36, Global Status Report on Alcohol). This is no benign problem; excess drinking has taken a toll on Hungary's health, and the incidence of death due to liver disease and cirrhosis also saw a large increase from the 1970s to the 1990s (Buda 64). Since the end of Soviet control of Hungary, the consumption of alcoholic beverages has remained at these high levels. This project, through a number of personal interviews, will entail exploring the causes for this drastic increase in alcohol intake among Hungarians and the people's perspectives of this change both on an individual basis and on that of the country.

Background:

Over the last few years, I have had the opportunity to travel to Hungary on a number of occasions and to get to know many people there from several generations. Hungary is a beautiful country with a very troubled past, most recently being subject to a Soviet communist dictatorship. As this regime ended only in 1989 (with the last occupying soldiers leaving in 1990), it is not difficult to see its remnants in the country, and the marks of the old dictatorship are most apparent in the people themselves. During my time in Hungary, I have heard many stories of people losing everything their families owned for generations, of highly educated professionals being forced to work blue collar jobs, of living with many people in the same apartment due to space restrictions, of fear and suspicion, disappearances, torture, and failed revolutions. It has never ceased to amaze me that this is not a distant history relegated to the history books: the very people who lived through these troubling events will sit across the table from you and very emotionally recount these stories that are obviously very close to the surface. These real life stories of what they went through and my experiences in Hungary as a whole have inspired my keen curiosity in Hungary and the Soviet rule that helped to shape it into the beautiful and troubled country it is today. One of my pastimes has become reading histories on Hungary, especially the events of the last century.

Since I began my medical studies last fall, health issues have naturally begun to catch my attention more, and I was intrigued to find in my readings on Hungary that alcoholism has not

always been the problem there that it is now and that it remarkably increased during the time of the Soviet occupation. I am no stranger to the fact that significant amounts of alcohol are regularly consumed by the general population there, as the family I normally stay with will drink up to two bottles of wine each night during a typical dinner. Wine is such a common drink in Hungary, people actually transfer it to plastic bottles and store it like soda or water. This is not the only favored alcohol, however; Hungary is well-known for its hard liquor called pálinka from distilled fruits that many people often make themselves. Ever since my first visit, I have found the very commonplace alcohol consumption intriguing, and the fact that this practice seems to have reached its current levels during the communist time period makes it even more so. I have long been interested in learning more about exactly how the communist dictatorship influenced the country and its people, something that books alone cannot portray. It is my hypothesis that the lack of freedom, loss of control over one's own life, fear, and stress that many people have described under Soviet rule in Hungary were major factors in driving the increase in alcohol use. While I cannot say whether the rise in Hungary's alcohol use was a result of the regime at the time, and while it may be difficult to ever know for sure, I am very excited to go and find out what can be learned by talking with the Hungarian people and discovering their opinions on why alcohol holds the place it does in their society.

I want to answer the following questions:

- How was alcohol consumption perceived by Hungarians living before and during the years of increase, and did their perception of alcoholism change over the years?
- What do Hungarians believe was behind the increase in alcohol intake?
- What do Hungarians believe is the cause of the continued high alcohol use today?

Description:

In order to better delineate what may have been the causes of the increase in alcohol consumption between the 1950s and the 1980s, which has remained high to this day, I would like to look into the perspectives of Hungarian people on alcohol use and alcoholism and how it may have changed throughout their lives. This will involve interviewing three groups of people, starting with those who lived during years before the Soviet rule began in 1945. Interviews will be conducted with Hungarians 75 and older, and questions will be asked concerning their memories on alcohol consumption and its place in society in their childhood, as well as whether they perceived changes in this regard throughout their lives and what they believe may have been the causes of these changes. Interviews will also be conducted with Hungarians who grew up during the Soviet occupation (those from 30 to 74 years of age). Questions will be posed regarding their perception of alcohol consumption throughout their lives, how it impacted their own lives, and again what they consider may be the origins of the increase in alcohol intake and why it has remained high until today. The last group to be interviewed will include those who grew up after the end of the Soviet occupation (ages 18 to 29) in order to determine how they view alcohol and what they perceive as reasons the consumption is so high in their country (see

appendices A and B for interview questions). I plan to also converse with physicians in Hungary who see the results of alcoholism in their practices, including the head of a foundation for recovering alcoholics in the country, to obtain their perspectives on alcohol use and what changes they have observed over the years, as well as what they believe may be behind Hungary's high alcohol intake.

In order to accomplish the project, I will leave for Hungary on the 1st of June, arriving in the capital, Budapest, on Wednesday the 2nd. My time in Hungary will last until Friday, the 30th of July, when I will return to Wichita. Throughout my two months in the country, I will conduct the interviews for my research. These interviews will take place in Budapest as well as Győr, Pécs, Debrecen, and Mosonmagyaróvár. While in Hungary, I would like to take advantage of my time there to learn more Hungarian as well by enrolling in a three week intensive Hungarian language program through the University of Debrecen in Budapest. This program will consist of half day classes each weekday and will last from June 7th until the 28th. I would also like to gain more experience in different medical settings, especially in a socialized health program like that in Hungary, by shadowing a physician at the FirstMed Centers in Budapest two or three days each week for the first three weeks in July. I am in the process of setting up this shadowing with the hospital.

Methods:

While in Hungary, I will stay with the Nyitrai family throughout the duration of my project. Interviewees will be enlisted from a variety of locations. Candidates will be approached, given a description of the project, and allowed to choose whether or not to participate. Consent to take part in the research will be obtained from all persons interviewed by form of written permission (see appendix C). In compliance with HSC exempt status, interviews will be recorded on a digital recorder with care taken to include no identifying information of the individual on the recording. Interviewees will also be encouraged to give no incriminating or harmful information pertaining to themselves in the interview. The majority of interviews with Hungarians aged 75 and above will be conducted at the Győri Katolikus Egyház Napköztiotthona, a retirement program for elderly citizens to come together each day for lunch and socializing. Persons between the ages of 30 and 74 will be acquired through convenience sampling. Interviews of young adults (aged 18-29) will be conducted among students at the Corvinus University of Budapest. In order to ensure that the interviewees are able to give a relevant perspective into alcoholism and this time period, those Hungarians in the two older age groups who lived outside of Hungary for more than five years between 1950 and 1989 will be excluded from the study. Hungarians from the younger age group who lived outside of Hungary for more than five years will also be excluded. As calculating an adequate sample size would be difficult, it is my intention to sample to saturation as far as is possible. Those meetings with specific doctors and researchers (listed below) will likely take place at their respective offices. Interviews will be conducted in Hungarian with the help of translators and, when possible, will be conducted in English.

Though I do not speak Hungarian conversationally, I will have the assistance of Levente and Emese Nyitrai as translators. I am currently learning basic Hungarian on my own through regular communication with friends in Hungary, as well as books and computer programs. I also plan to take the intensive Hungarian course in Budapest. As a result, I hope to more efficiently communicate in Hungarian by the time my stay in Hungary is complete.

My application for HSC exempt status and project protocol were submitted to the Human Subjects Committee on February 11th.

Contacts:

<i>Physician Mentor</i> John Delzell, MD Associate Professor and Associate Chair for Education Family Medicine	<i>Human Subjects Committee Resource</i> <i>Principal Investigator</i> Christopher Crenner, MD, PhD Associate Professor and Chair of History and Philosophy of Medicine
Emese Nyitrai Student, Corvinus University in Budapest	<i>Lodging</i> Levente Nyitrai Political Officer, British Embassy 1132 Budapest Kresz Geza u. 53/A, 3/3
Dr. Földi Klára General Practitioner (Gyermekeorvosi Rendelő) Kovács Csaba Founder of Félúton Alapítvány 1081 Budapest	
Orczy u. 27 Egyházmegyei Papi Otthon Idősek Napközotthona Retirement Center 9021 Győr	Dr. Gábor Feller Psychiatrist Petz Aladár Megyei Oktató Kórház II
Káptalandomb 26 Phone: 00-36-96-312-153 Dr. Sue McGladdery Medical Director FirstMed Centers Kft. Hattyúház, Hattyú u. 14 H-1015 Budapest	Debreceni Nyári Egyetem Budapesti Nyelviskolája Language Program <u>Dr. Vermes Tamás</u> Director of Karolina Kórház (hospital) 9200 Mosonmagyaróvár Régi vámház tér 2-4

Félúton Alapítvány is a foundation to "heal people suffering from alcohol addictions... and educate young people about alcohol and addiction." (www.feluton.hu)

Budget:

Airfare to and from Budapest, Hungary

\$1513 (see attached itinerary--subject to change until purchase finalized)

Traveling expenses within Hungary

\$200 (train/bus between cities, metro pass in Budapest)

Food expenses

\$300 (\$50/week x 6 weeks)

Lodging provided by Nyitrai family

Total: \$2013

As a medical student, this project will not be possible for me without assistance in funding. Thank you for considering my proposal.

Any expenses incurred above the amount provided by the fellowship will be covered from my own funds.

Goals

The summer ahead holds many exciting prospects, and I aim to get as much out of the opportunity as possible. In addition to improving my Hungarian language skills, with this project I most hope to get a glimpse into the time of the Soviet control of Hungary and the changes it wrought, particularly as these changes apply to the level of alcohol consumption and its toll on the populace. The stories and perspectives of the people who lived through this time period will provide invaluable insight, such as could never be found in a book, into the reasons behind the greater alcohol use and what the increase meant to the Hungarian people. Through my conversations with people who are part of this history, some of whom may not be able to share their stories much longer, I hope to also gain some understanding of the effects of the factors that brought on the high rate of consumption and their ultimate impact on the people involved.

I want to thank the Clendening Fellowship committee for your consideration of my project.

Resources:

Bereczki, Mrs. Sándor. "Hungary: Drug Consumption and Government Policy." Interview by Gusztáv Kosztolányi. *Ce-review.org*. Central Europe Review, 19 Feb. 2001. Web. 12 Oct. 2009. <<http://www.ce-review.org/01/7/csardas7.html>>.

Buda, Béla. "Epidemiology of Alcoholism in Hungary." *Alcohol Consumption and Alcoholism in Hungary*. Budapest: Akadémiai Kiadó, 1997. 50-66. Print.

Country Cooperation Strategy: Hungary. Issue brief. World Health Organization, Apr. 2007. Web. 12 Oct. 2009. <http://www.who.int/countryfocus/cooperation_strategy/ccsbrief_hun_en.pdf>.

Global Status Report on Alcohol: Hungary. Rep. World Health Organization, 2004. Web. 12 Oct. 2009. <http://www.who.int/substance_abuse/publications/en/hungary.pdf>.

"Health in Hungary." *Debrecen University Faculty of Health*. Debreceni Egyetem OEC Egészségügyi Kar, 2009. Web. 12 Oct. 2009. <<http://odin.de-efk.hu/content/view/1021/>>.

Skog, Ole-Jorgen, and Zsuzsanna Elekes. "Alcohol and the 1950-90 Hungarian Suicide Trend: Is There a Causal Connection?" *Acta Sociologica* 36.1 (1993): 33-46. JSTOR. Sage Publications, Ltd. Web. 12 Oct. 2009. <<http://www.jstor.org/stable/4200830>>.

Appendix A: Questions for Interviews with Hungarians Over the Age of 30

1. In what year were you born?
2. Where in Hungary are you from? Have you lived in Hungary for the majority of your life? If you lived outside of Hungary, when was this?
3. When you were a child, was alcohol consumed in your home? If so, how often and in what quantities? What kind of alcohol?
4. Who took part in alcohol consumption in your home? What were their reasons, ie.: local customs, social pressures, depression, escape, etc.?
5. Was drinking alcohol prevalent outside the home, that you are aware of? If so, where did this take place?
6. Do you recall problems with alcoholism in your family or the community when you were a child? If so, what do you remember concerning alcoholism then?
7. As you grew older, did you notice changes:
 - a. in the amount of alcohol consumption in the community?
 - b. in the type of alcohol consumed?
 - c. in the frequency of alcohol consumption?
 - d. the reason alcohol was consumed?
 - e. in the location of alcohol consumption?
 - f. in problems concerning alcoholism in the community? Did you know anyone who drank alcohol excessively? How much would you consider excessive?
8. If you did notice changes, what do you believe was the cause behind them?
9. Data shows that alcohol consumption in Hungary increased drastically between the 1950s and the 1980s. What do you suspect are the reasons for this increase?
10. Alcohol consumption in Hungary remains high today. Do you think this is a problem? What do you believe the causes might be?

Appendix B: Questions for Interviews with Hungarians Under the Age of 30

1. In what year were you born?
2. Where in Hungary are you from? Have you lived in Hungary for the majority of your life? If you lived outside of Hungary, when was this?
3. Is alcohol consumed in your home? If so, how often and in what quantity? What types of alcohol?
4. Who takes part in alcohol consumption in your home? What were their reasons, ie.: local customs, social pressures, depression, escape, etc.?
5. Did this ever lead to problems in your immediate or extended family?
6. Is drinking prevalent outside the home? If so, where does this take place?
7. Are you aware of problems with alcoholism or excessive alcohol consumption? How much would you consider excessive?
8. Do you know of people who consume alcohol excessively or have problems with alcoholism?
9. Have you noticed any changes in your life in terms of alcohol consumption in society?
10. Data shows that alcohol consumption in Hungary increased drastically between the 1950s and the 1980s. What do you suspect were the reasons for this increase?
11. Alcohol consumption in Hungary remains high today. Do you think this is a problem? What do you believe the causes might be?

Appendix C: Consent Form

The Hungarian Perspective on the Rise and Sustained Level of High Alcohol Consumption

Katie Grelinger

kgrelinger@kumc.edu

I am a medical student at the University of Kansas School of Medicine, and I am conducting interviews for a summer research project. I am studying the perspective of Hungarians on the rise in alcohol use in Hungary between the 1950s and 1980s and the causes behind the rise.

In this interview, I will be asking questions on your experiences and opinions on alcohol in Hungary throughout your life. Please feel free to expand on any question or discuss issues related to the question. I encourage you not to give any information in the interview that may in any way be harmful or endangering to yourself. If there are any questions you do not feel comfortable or would prefer not to answer, please inform me and we can either stop the interview or move on to the next question, as you prefer.

All information will be confidential. In order to ensure confidentiality, no full names, addresses, phone numbers, ID numbers, or birthdates will be collected. Only my faculty adviser and I will have access to the information, and it will either be destroyed or kept in a secure location at the conclusion of the project.

Participant Agreement:

I understand the intent and purpose of this research and that my participation is voluntary. If, for any reason, at any time, I wish to stop the interview, I may do so without having to give an explanation.

I give the researcher permission to quote from my interview in the presentation of the research, with the understanding that my confidentiality will be maintained and quotes will remain anonymous.

Having read and understood the above form, I give my consent to participate in this interview.

 Participant's signature

 Date

 Interviewer's signature

*form adapted from template provided by Bard College Institutional Review Board
<http://inside.bard.edu/irb/ExampleInterviewConsentForm.htm>

Consent Form-- Hungarian

Katie Grelinger
kgrelinger@kumc.edu

A University of Kansas School of Medicine orvostanhallgatója vagyok, és egy tanulmányhoz végzek felméréseket. Kutatásomban vizsgálni szeretném a megnövekedett alkoholfogyasztás okait, elsősorban az 1950-es és az 1980-as évek közötti időszakban. Ebben az interjúban kíváncsi leszek az Ön tapasztalataira és véleményére a magyarok alkoholfogyasztási szokásaival kapcsolatban. Mindezt nyugodtan kifejtheti részletesebben is.

Az Önnek kellemetlen részleteket természetesen nem kívánom, hogy megossza velem. Amennyiben olyan kérdést teszek fel a beszélgetés során, mely érzékenyen érinti, vagy amire nem szívesen adna választ, kérem jelezze, és befejezhetjük az interjút, vagy továbbléphetünk egy másik kérdésre.

Minden választ bizalmasan kezelek. Ennek érdekében teljes neveket, pontos címeket, telefonszámot, személyi igazolvány számot és születési dátumot kérem ne tüntessen fel. Az Ön által elmondott információhoz kizárólag nekem és a kutatásvezetőmnek lesz hozzáférése, és a projekt befejeztével azt vagy megsemmisítjük, vagy elzárjuk.

Részvételi nyilatkozat:

Tisztában vagyok ennek a felmérésnek a szándékával, azt támogatom, valamint tudom, hogy részvételem önkéntes. Ha bármi okból kifolyólag, bármikor fel akarom függeszteni a beszélgetést, erre módom van akár indoklás nélkül is.

Felhatalmazom a kutató orvostanhallgatót az interjú elkészítésére, annak tudatában, hogy csak nevem elhallgatásával idézhet beszélgetésünkből valamint az információkat bizalmasan kezeli. A fentiek elolvasásával és tudomásulvételével belegeyzem az interjúba.

Dátum:

interjút készítő aláírása

résztevő aláírása

Coping with Cancer: An Analysis of Social Support Services for Oncology Patients in Kansas City

Table of Contents

Introduction

Background
Personal Motivation

Research
Research Goals
Timeline

Methodology

Coping with Cancer: An Analysis of Social Support Services for Oncology Patients in Kansas City

John Hunninghake
Clendening Fellowship
Summer 2010

Appendix

Appendix

List of Nonprofit Agencies and Cancer Clinics in the Kansas City Area (for patients who are asked to complete social support services)

Survey

Survey Interview Consent Form

Coping with Cancer: An Analysis of Social Support Services for Oncology Patients in Kansas City

Table of Contents

Introduction.....	3
Background.....	3
-Personal Motivation	
Description.....	5
-Project Goals	
-Timeline	
Methodology.....	7
-Approval, Permission, and Endorsements	
Budget.....	9
Contact Information.....	10
Bibliography.....	11

Appendix

List of Nonprofit Agencies and Cancer Clinics in the Kansas City Area (for patients who ask about available social support services)

Survey

Survey Interview Consent Form

Coping with Cancer: An Analysis of Social Support Services for Oncology Patients in Kansas City

INTRODUCTION/PURPOSE OF THE RESEARCH

Cancer is a chronic illness that requires comprehensive treatment and care that go beyond the medical world's "standard-of-care." Meeting the psychosocial needs in cancer care is generally recognized as an important component in the overall quality-of-life of patients undergoing cancer treatment (Greer from Matthews, et al., 2004). Reducing the burden of suffering from cancer is therefore important to a patient's quality-of-life during treatment. Social support services are available in communities in order to assist cancer patients with psychosocial issues that many cancer patients face after their initial diagnosis. The goal of this project is to research the use of social support services by individuals who are currently undergoing treatment for cancer in the Kansas City area. The study is a non-interventional, epidemiological analysis that asks patients voluntarily to fill out a written survey or respond orally to questions about the type of support services that they use. This project aims to gather statistics about the type and frequency of services that patients use, and then correlate that information with the patient's opinion about the benefits and short-comings of the services. The resulting information can be used by healthcare providers and nonprofit agencies to respond more effectively to the needs of cancer patients by determining possible reasons that some social support services are used more often than others.

BACKGROUND

Cancer is a potentially fatal illness that is often characterized by a stigma; therefore, cancer patients require additional social support to successfully complete the treatment process. **Social support services are defined as "those programs or services offered by a medical clinic or a nonprofit agency that assist patients and their families in handling the myriad physical, emotional, social, and practical problems that follow a cancer diagnosis and its subsequent treatment"** (Murphy from Matthews, et al., 2004). These free-of-charge services are usually offered by local and national nonprofit agencies in order to assist cancer patients with various aspects of the cancer treatment process. A full list of social support services and various nonprofit agencies is contained in this project's survey. Examples of these support services include: support groups, peer-to-peer counseling, transportation, group workshops, educational information about cancer, etc. However, many different ideas existed about what constitutes a "social support service"; therefore, this project will identify the programs and services in the Kansas City area that cancer patients consider as "supportive" for them during their cancer treatment.

Considerable evidence suggests that social networks and support are important contributors to decreased distress and improved psychosocial adjustment among patients at all stages of the disease trajectory (Kornblith 2001). A study by Alex Matthews, et al., entitled "Oncology professionals and patient requests for cancer support services" provided detailed information about patient inquiries to healthcare providers for certain social support services. According to Matthews, cancer education and counseling were the two forms of services that were requested the most. The article indicates that "future studies are needed to determine if patients' requests are actually fulfilled" (736:2004). Other studies indicate that social support services can be perceived as beneficial or detrimental by the patient, depending on the individual person. According to Helgeson and Cohen, discussion groups have as much potential to adversely affect patients' illness reactions as they do to positively influence these reactions, due to various reasons (1996:144). By assessing the specific use of social support services in the Kansas

City area, this project will collect data about the type of programs used by patients, the frequency, and the perceived benefit of different types of services on the patients.

Most studies in the past have evaluated how cancer patients are socially-supported after the completion of treatment. I believe that my study is unique because it evaluates the social support of patients *during* the treatment process, and the psychosocial effect of those services on the patient. My research study is not using complex methods to quantify the mental status of the patient. Instead, the survey asks about the importance of the social services for the patient, whether the service helps the patient cope with the cancer treatment, and what type of "support"—emotional, physical, spiritual, financial, social, psychological, or other—that the social support services offer to patients who use them. According to a multi-study review by Hegelson and Cohen, cancer patients identified "emotional support" is the most helpful kind of support during the disease process (1996:136). However, I believe patients who use social support services will identify "physical" support as another important type of support, especially during the cancer treatment. Ultimately, an analysis of the data from the surveys will show: how many patients use social support services during treatment; if those services are helping them to cope with the cancer treatment; and what type of support those services provide to the patient.

Personal Motivation

As an undergraduate, I majored in Medical Anthropology at Southern Methodist University and therefore developed a strong interest in the humanistic side of medicine. For an undergraduate thesis in 2007, I completed a research project in Ecuador and Costa Rica through the Richter Fellowship program that resulted in publication of the results. My project entitled, "Environmental Volunteer Organizations: A Vehicle for Economic Sustainability," evaluated the effect of volunteer organizations on the economic prosperity of the surrounding, local communities. The project involved interviewing community leaders in the rural areas of Ecuador and Costa Rica in order to gain their perspective about the growth of the international volunteer organizations in their villages. Although it was not medically-related, this ten-week experience taught me how to develop a research project properly, how to execute it, and especially how to adapt when plans change.

Personally, I developed the idea for this project because of my strong interest in the psychosocial needs of patients with chronic illness. I am particularly interested in cancer patients because I would like to be an oncologist in the future. I developed my strong interest in oncology after I began volunteering in October 2009 for a local nonprofit agency called Cancer Action. As a volunteer driver for Cancer Action, I transport patients to-and-from appointments because they do not have someone to transport them. It is one example of a social support service that helps to ease the burden that cancer patients feel while are undergoing intense medical treatment for their disease. Another example is when I volunteered for the SolarisCare Cancer Support Center in Perth, Australia, for four months back in 2006 as an undergraduate study-abroad student. The Center is physically located in the middle of the Sir Charles Gairdner Hospital, a major public teaching and research hospital in Perth. The Center is a volunteer organization that is supported by the hospital but funded by community donations. It was founded by an Australian oncologist, named Dr. David Joske, for the specific purpose of providing various means of supportive care to all people with cancer, their families, and caregivers. Supportive care services include: meditation, counseling, expressive art therapy group, massage therapy, Reflexology, Reiki, and others. With the patient-centered model of healthcare today, more importance is being addressed by healthcare facilities to address all the needs of the patient. I believe that the Solaris Cancer Support Center is an excellent model for how social support services can be integrated into mainstream medical care for cancer patients.

I have a sincere desire to passionately pursue this project with great zeal and earnest for the benefit of the psychosocial needs of cancer patients. After spending hours reading the Clendening Fellowship proposals from the previous five years, I became feverishly excited about the possibilities of my project. The Clendening Fellowship offers an extremely unique opportunity to earn funding for a project that I believe will set the stage for future research in the Kansas City area and places like SolarisCare Cancer Support Center in Perth, Australia. As a possible extension to this project in the future, I would like to research the differences between the delivery methods of social support services in Kansas City compared to a place like SolarisCare. I am already excited at the possibility to expand this research idea in the future.

With so many previous Clendening projects that performed research in other countries, I believe that my project has an extraordinary opportunity to make a real impact on the lives of local citizens in the Kansas City area. With the high prevalence of cancer and a true need for awareness about social support services, all of the nonprofit agencies expressed excitement about the project. All of them were truly surprised that a medical student would be conducting it! In addition, the Kansas City Cancer Center is very interested to learn the results of the project. Currently, they do not employ any social workers to assist their patients with social support services; however, they suggested that the results might convince them to incorporate social workers into their staff. Most importantly, I believe that the results of this project can aid the University of Kansas by improving the services and direction that they offer to their patients, in regards to social services. Ultimately, through my research and eventual publication, I hope to bring even more awareness to cancer patients undergoing treatment about the available support services.

DESCRIPTION

Project Coordinator: John Hunninghake

Faculty Mentor: Dr. Sarah Taylor, M.D.

Specific Aims	Methods
(1) To assess the types of social support services that are used by cancer patients in the Kansas City area (2) To evaluate how social support services help patients during their treatment (2) To increase awareness about the social support services available to cancer patients.	(1) Distribute surveys to cancer patients over a 16-week time period. (2) Conduct structured interviews of cancer patients with the exact questions from the survey.

My project intends to answer the following questions:

1. Do patients use social support services while they are undergoing treatment? If so, which one(s)?
2. What services or programs do patients consider as "social support services"? What agency or organization provides those services?
3. What services or programs are used the most by patients? Why?
4. If patients use social support services, do those services help the patients cope with the burden of cancer treatment?
5. What social support services do patients *wish* would be offered?

Specifically, the survey and the interview components of this project intend to:

- Identify the **number of cancer patients** who use nonprofit agencies for social support services
- Identify **where** patients receive their services, and **why/how** that agency was chosen/discovered
- Identify what **programs and services** that local cancer patients consider as "supportive" during their cancer treatment process
- Identify the **most utilized** support services by cancer patients
- Identify **why** patients use one support service rather than another
- Identify the **perceived** effect of support services on the patient's **quality of life**
- Identify the **importance** of support services to patients
- Identify the **type of support** that patients receive from social support services
- Identify **additional support services** that could be beneficial to patients
- *Indirectly acknowledge the existence of the available social support services in the KC area*

An analysis of the statistical patterns in the surveys intends to:

- Identify the **main sources** of social support in the Kansas City area.
- Correlate the **patients' perceived benefit** of the support services with the **type and frequency** of services used by the patients
- Provide **useful data** to nonprofit agencies and healthcare providers for planning new initiatives, refining existing programs, and targeting materials to specific healthcare groups.
- Assess how well cancer patients' **social needs** are being met

Project Goals:

- Sixteen-week timeline for survey distribution (March 29 – July 26, 2010)
- At least total 1000 survey responses ($n = 1000$) in order to reduce error and account for variability [Average of 10 completed surveys per week per clinic (8 total clinic locations among the KU Cancer Center and the KC Cancer Center locations)]
- At least 150 patient interviews total - average 5 interviews/day at each clinic (8 total clinical locations) for 32 days
- Clendening Project Presentation
- Write an article to for local and possible national publication

Hypotheses:

- "Counseling" will be the most used form of a social support service by cancer patients, which is consistent with the research (Murphy735:2004).
- Patients who use social support services will identify "emotional" and "physical" support as the most important types of support during medical treatment.
- Patients who participate more in social support services believe that coping with the burden of cancer treatment is easier for them than patients who do participate less in social support services.

8-Week Project Timeline:

March 8-12, 2010 (*does not count toward project time*) - Continue to interview physicians, social workers, and nonprofit agency representatives to refine the content of the survey

March 29, 2010 – Official beginning of survey distribution (pending HSC approval); cancer clinics begin asking patients to voluntarily complete the survey, starting at 8am.

May 10-28, 2010 (3 weeks) – Begin patient interviews at clinical locations; Verify distribution of surveys at the various clinics; Mid-project statistical analysis of survey results at 3 weeks

May 14th, 2010 - Pick up completed surveys from the survey collection container at each clinical location.

May 28th, 2010 – Pick up completed surveys from the survey collection container at each clinical location.

May 31-June 25, 2010 – Air Force Commissioned Officer Training

June 28 - July 23, 2010 (4 weeks) –Patient interviews; Verify distribution of surveys at the various clinics by calling the representative of each clinical location

June 28th, 2010 – Pick up completed surveys from the survey collection container at each clinical location.

July 12th, 2010 – Pick up completed surveys from the survey collection container at each clinical location.

July 23rd, 2010 – Official end of survey distribution; at 5pm, cancer clinics stop asking patients to voluntarily complete the survey

July 26th, 2010 – Pick up survey collection containers from each location.

July 26-30, 2010 (1 week) – Compile data, analyze, and complete the final report with the survey statistics. Begin full analysis of research data with the intention of eventual results' publication.

METHODS

Specific Aims	Methods
(1) To assess the types of social support services that are used by cancer patients in the Kansas City area (2) To evaluate how social support services help patients during their treatment (2) To increase awareness about the social support services available to cancer patients.	(1) Distribute surveys to cancer patients over a 16-week time period. (2) Conduct structured interviews of cancer patients with the exact questions from the survey.

The main methodology of this project is the **distribution of a survey** to eight different cancer clinic locations around the Kansas City metro area. The locations of the local cancer clinics include: University of Kansas Hospital Cancer Center, Kansas City Cancer Center (7 out of 11 clinical locations—includes Central, East, North, Shawnee Mission, South, Southwest, and West offices; excludes Business Office, Blue Springs, Medical Mall, West Radiation is part of West Office). The clinics were chosen based on

patient volume, presence of two or more medical doctors, location, and an agreement to allow distribution of the survey.

The study is a non-interventional, epidemiological analysis where patients fill out a written survey or respond orally to questions about the type of support services that they use. With the statistical data, this project aims to correlate the type and frequency of services that patients use with the patient's perceived effect of these programs.

The purpose of the written survey is to collect data about the use of social support services by patients who are undergoing treatment for cancer. "Cancer treatment" is defined as a current chemotherapeutic regimen, radiation, or a combination of chemotherapy and radiation. The survey will be distributed by the cancer clinics beginning March 29, 2010 and will cease distribution on July 26, 2010. Currently, I have gained initial approval from the Kansas City Cancer Center and University of Kansas Cancer Center to distribute the survey and conduct interviews at their locations. I am currently in communication with a representative from each clinic to develop a survey distribution procedure for the clinic. Each clinic will have a slightly different procedure for the survey distribution and interview conduction depending on its setup and arrangement. In general, the front desk employee will ask each eligible patient for voluntary completion of the survey. An eligible patient means that he or she is present at the clinic for cancer treatment, and not present at the clinic as a "new patient." If an eligible patient asks questions about the survey before beginning, the patient will be handed the cover sheet for the "Consent Form" to explain the project. After voluntary completion of the survey, the patient will personally place the survey through a slit in a designated secure container in order to protect patient privacy. Data collection will begin on March 29, 2010. I will collect the surveys from each clinical location every two weeks in order to protect the information on the completed surveys and to assess the amount of completed surveys. The surveys will be collected from each clinic every two weeks beginning May 14, 2010, and continuing on the dates of May 14, May 28, (not June 11 due to Air Force training), June 28, July 12, and July 26. The data collection period will close on July 26, 2010.

In addition to the survey, **patient interviews** will be conducted. The purpose of the patient interviews is to ensure proper completion of the surveys and to increase the number of completed surveys. I will spend four days at each clinical location, for a total of 32 days of patient interviews among the eight clinical locations. I will ask each eligible patient who is checking in for an appointment to verbally complete the survey in a private exam room. If the patient agrees, I will have them sign the "Consent Form" (please see the Appendix for the form). In the private room, I will ask the exact questions that are on the survey and then mark the answers on the survey. I will not ask any additional questions that are not on the survey. I will not write any additional physical information about the patient on the survey. I will not physically examine the patient in any way. Upon completion of the interview, I will have the patient visually verify the answers on the survey, and then sign a designated line on the "Consent Form" indicating that they verified the survey. Ultimately, the interviews are intended to ensure adequate completion of the survey and to increase the number of completed surveys. An increased number of completed surveys will help reduce variability and error in the final research statistics.

I have currently submitted an Application for Exempt review to the IRB Human Subjects Committee. According to the IRB Administrator, Dan Voss, the committee is currently busy with applications and it will take about 10 days for approval. However, Dan Voss has reviewed my survey questions. He believes that my survey is low-risk and states, "None of your questions raise any red-flags of which the IRB would be concerned." Additionally, I have submitted an application to the University of Kansas Cancer Center IRB committee, and am currently awaiting approval.

Approval, Permission, and Endorsements

The University of Kansas Cancer Center has agreed to allow the distribution of the survey and the conduction of interviews at their Cancer Center, pending official approval from the Cancer Center IRB Committee. I have been in contact with the Executive Director, John Hennessey, of the Kansas City Cancer Center about approval to distribute client surveys on seven of their ten clinical locations. He forwarded on the survey to his Compliance Officer for official approval, but has given unofficial permission assuming that there are no complications with his Compliance Officer's review. Two social workers at the KU Cancer Center, Jan Peterson and Mary Moody, have reviewed my survey. They both agree that the survey will collect valuable information that "could greatly benefit cancer patients and the community-efforts to assist them."

With regards to the nonprofit agencies in the community, I have received an overwhelming response of positive support. I have received permission to use *Turning Point* in my survey from Moira Mulhern (CEO of *Turning Point*) and Cindy Raedle (the Director of Community Outreach at *Turning Point*). They have both strongly endorsed the project. I have also received approval to use *Cancer Action* in my survey from Karla Nichols (the Executive Director at *Cancer Action* and the Director of the Cancer Coalition in Kansas City). I have spoken with Vangi Rich, the Executive Director at the *R.A. Bloch Foundation*, and received approval to use them in my survey. Sandy LeRoux, who is the Director of Community Affairs at the American Cancer Society chapter in Kansas City, has reviewed my survey and given me permission to use the organization in the survey. I have contacted the National Cancer Institute, and am currently awaiting a response. All the directors that I contacted were unanimous in their support for the research study; they believe it will gather valuable data that can be used to further the collaboration of local agencies in offering needed support services to cancer patients.

BUDGET

Printing costs for the survey, informed consent page, and other documents	
2 pages per survey * 1000 copies = 2000 pages * \$.05/page =	\$100
2 pages per informed consent * 200 copies = 400 pages * \$.05/page =	\$20
1 box/ clinical location * 8 locations * \$5/box =	\$40
Transportation - travel to and from local cancer clinics	
Survey distribution/pickup = \$5/day in gas * 5 days =	\$25
Interview days=\$5/day gas * 32 days =	\$160
June and July Rent in Kansas City = \$700/month x 2 =	\$1400
Food/groceries for 8 weeks =	\$600
Research Material (books)	
"Cancer Care for the Whole Patient" by Nancy Adler and Ann Page =	\$42.26
"Anticancer: a new way of life" by David Servan-Screiber =	\$19.00
Total Budget Costs:	\$2406.26

I understand that the Clendening Fellowship will not be able to cover all of my project and living expenses during the eight weeks of the research study. If I am accepted for the Clendening Fellowship, I plan to use my savings to supplement the remainder of the budget costs. I would greatly appreciate the experience that Clendening has the chance to offer me, and would be very grateful for the opportunity to explore this important social issue for the sake of the patients!

Contact Information

Dr. Sarah Taylor, M.D. (faculty mentor)
Medical Oncology
University of Kansas Cancer Center

John Hennessy
Executive Director
Kansas City Cancer Center

Karla Nichols
Executive Director
Cancer Action and the Kansas City Cancer Coalition

Dr. Moira Mulhern, PhD
Co-Founder/CEO
Turning Point

Cindy Raedle
Director of Community Outreach
Turning Point

Vangi Rich
Executive Director
R.A. Bloch Cancer Foundation

Sandy LeRoux
Director of Community Affairs
American Cancer Society

Jan Peterson and Mary Moody
Social Workers
University of Kansas Cancer Center

BIBLIOGRAPHY

- Adler, Nancy E. and Ann E. K. Page. "Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs" National Academies Press. 2008. (Accessed online January 23, 2010 http://www.nap.edu/openbook.php?record_id=11993&page=1#)
- Greer S, Moorey S, Baruch J "Evaluation of adjuvant psychological therapy for clinically referred cancer patients." 1991. *British Journal Cancer* 63:257-260.
- Helgeson, Vicki S. and Sheldon Cohen. "Social Support and Adjustment to Cancer: Reconciling Descriptive, Correlational, and Intervention Research." *Health Psychology*, 1996, Vol. 15, No. 2, 135-148.
- Kornblith AB, Herndon JE II, Zuckerman E, Viscoli CM, Horwitz RI, Cooper MR, Harris L, Tkaczuk KH, Perry MC, Budman D, Norton L, Holland JC. "Social support as a buffer to the psychological impact of stressful life events in women with breast cancer. 2001. *Cancer* 91:443-454.
- Matthews, B. Alex "Oncology professionals and patient requests for cancer support services." *Support Care Cancer* (2004) 12:731-738
- Matthews, B. Alex "Healthcare Professionals' Awareness of Cancer Support Services" *Cancer Practice*. January/February 2002.
- Murphy, GP, Lawrence W Jr, Lenhard E Jr (1995) American Cancer Society textbook of clinical oncology (2nd edition). Atlanta, GA: American Cancer Society.
- Wolcott, Deane L. et al. "Patient Support Services & Patient Satisfaction." *Oncology Issues*. January/February 2009.

List of Participating Agencies and Cancer Clinics in the Kansas City Area (to be handed out to patients who ask for more information about local social support services)

Local and National Nonprofit Agencies (listed in alphabetical order):

American Cancer Society

www.cancer.org

1-800-ACS-2345

Cancer Action

www.canceractionkc.org

913-642-8885

National Cancer Institute

www.cancer.gov

1-800-4-CANCER

R.A. Bloch Cancer Foundation

<http://blochcancer.org>

1-800-433-0464

Turning Point

www.turningpointkc.org

913-383-8700

Local Cancer Clinics:

Kansas City Cancer Center

<http://www.kccancercenter.com/support-resources/overview/>

University of Kansas Cancer Center

<http://cancer.kumc.edu/>

913-588-1227

Introduction

The World Bank has a dramatic impact on our health. Scientists have shown a direct correlation between diet, obesity, and a number of chronic diseases. These include type II diabetes, cardiovascular disease, stroke and cancer. These diseases were once thought to be a problem limited to higher-income countries. However, recent studies have shown that nutritional diseases are becoming a major problem in lower-income countries too. The problem is even more acute in countries where the prevalence of obesity is growing rapidly, but poverty rates and malnutrition remain high. For example, the World Health Organization estimates that 30% of Guatemalan women and 16% of Guatemalan men are obese, yet 56% of people living in Guatemala are living below the poverty level.

Ensuring sustainable food supply is the first step in ensuring the nutritional health of a population and preventing diet-related chronic diseases. Guatemala provides a perfect opportunity for investigating this connection due to the combination of poverty, malnutrition, obesity, and a rapidly rising population, who are involved in agriculture and the food supply chain. Little is known about the impact of sustainable agriculture programs on food supply in lower-income countries. For these reasons, I am proposing an eight-week study in Guatemala during the summer of 2010 to investigate and document the impact of sustainable agriculture on food supply, environment, and population health in the following proposal. I detail my methods and resources I plan to utilize in this proposal.

Sustainable Agriculture's Impact on Food Supply in Rural Guatemala

Jenna Kennedy

2010 Clendening Summer Fellowship Proposal

Background

I have a long history with agriculture and have had experiences have greatly influenced my desire to pursue medicine. As a young child, my father owned a tractor for my father on our family's farm in no other states. This early career in agriculture lasted until I turned 10, which point my father sold me a tractor and I started to farm. He made it clear that I was excellent farm help and that I should plan to make a career of farming so I went to the local community college to earn my certified nurse aide (CNA) because I like the idea of this CNA training was my start in healthcare. By the time I spent working on the farm for a big impression on me. As I grew older and became more mature with how humans impact their environment, I realized that my family's economic endeavors in farming were a prime source of this impact. When I went to college and reached the end of my undergraduate degree, I decided to major in natural resources and environmental science. This combination of fields allowed me to pursue a career in medicine alongside my interest in the environment.

During my junior year of college, I took a class that changed my life forever. The course was titled "Hunger and Poverty" and it was offered by the Department of Agriculture. Our professor had spent years of his life working on sustainable farming and the green revolution. At first, we had seen the pros and the cons of agriculture in lower-income countries. The professor told us that there are millions of hungry people in this world and repeating "hunger" and "poverty" practices is not the solution. The hunger problem is not just in our world, it's in the world. I spent the summer of 2009 in Guatemala, and I spent the summer of 2010 in Guatemala and I spent the summer of 2011 in Guatemala.

Introduction:

The food we eat has a dramatic impact on our health. Scientists have shown a direct correlation between diet, obesity, and a number of chronic diseases. These include type II diabetes, cardiovascular disease, stroke and cancer.¹ These diseases were once thought to be a problem limited to higher-income countries. However, recent studies have shown that nutritional diseases including obesity impact lower-income countries, too.² The problem is even more complex in countries where the prevalence of obesity is growing rapidly, but poverty rates and malnutrition remain high. For example, the World Health Organization estimates that 30% of Guatemalan women and 16% of Guatemalan men are obese³, yet 56% of people living in Guatemala are living below the poverty level.⁴

A healthy, sustainable food supply is the first step in ensuring the nutritional health of a population and preventing diet-related chronic diseases. Guatemala provides a unique opportunity for investigating this connection due to the conflation of poverty, malnutrition and obesity, and a mostly rural population⁵ who are involved in agriculture and the food supply chain. Little is known about the impact of sustainable agriculture programs on healthy food supply in lower-income countries. For these reasons, I am proposing an eight-week study in Guatemala during the summer of 2010 to investigate and document the impact of Semilla Nueva, a development organization that helps farmers implement sustainable farming practices, on the local food supply, environment, and population health. In the following proposal, I detail the methods and resources I plan to utilize in this study.

Background:

I have a long history with agriculture, and these past experiences have greatly influenced my desire to pursue medicine. As a youth, I started driving the tractor for my father on our family's farm in northwest Kansas. This early career in agriculture lasted until I started high school, at which point my father told me I needed to find another job off the farm. He made it clear that I was excellent farm help but that I shouldn't plan to make a career of farming, so I went to the local community college to earn my certified nurse aide (CNA) license. Little did I know that this CNA training was my start in healthcare, but the time I spent working on the farm left a big impression on me. As I grew older and became more in-tune with how humans impact their environment, I realized that my family's economic endeavors in farming were a prime example of this impact. When I went to college and searched for a career, I chose microbiology with a secondary major in natural resources and environmental science. This combination of fields allowed me to pursue a career in medicine alongside my interests in the environment.

During my junior year of college, I took a class that changed my life forever. The course was titled "Hunger and Poverty," and it was offered by the Department of Agriculture. Our professor had spent most of his life working on sustainable farming and the green revolution in Africa, and he had seen the best and the worst effects of agriculture in lower-income countries. His two-fold message was clear: there are millions of hungry people in this world, and exporting North American farming practices is not the solution to the hunger problem. In addition to my initial curiosity about farming's footprint on the environment, I began to question the impact of farming on nutrition and hunger issues.

Following graduation from college, I had a one-year fellowship with the Federal Office of Rural Health Policy. This U.S. Department of Health and Human Services office is charged with promoting access to health care services in rural America. In addition to ensuring access to health clinics and hospitals in small communities like the one in which I was raised, the office is also concerned with access to other community resources, such as gyms, parks and grocery stores. Most of my co-workers didn't grow up in rural areas, so I quickly became the farming "expert" in the office. They would drill me with questions about the Farm Bill and the farm subsidy programs contained within it. The commodity subsidy programs are complex, but I found it much easier to explain the structure of these programs than it was to defend keeping these programs intact. These subsidies have been widely criticized for doing little to promote a nutritionally balanced and sustainable food supply in our country. Through this fellowship experience, I obtained firsthand knowledge of the resources and programs that are designed to develop and maintain a healthy population. While it would require additional research to know exactly which specific policy changes are needed to promote a healthy, sustainable food source, I strongly believe farming practices must change before our food supply becomes more healthful and Americans of all socioeconomic classes begin to improve their diets.

Description:

Each of these experiences in agriculture shaped my journey to medical school, but more importantly, they influenced my desire to study sustainable agriculture's impact on providing a healthier source of food for the local population. I am fortunate to know Joseph Bornstein who is currently working as an Associate with Semilla Nueva⁶ near Xela (Quetzaltenango), Guatemala. Semilla Nueva is an agriculture development organization that engages local community members (*promotores*) to adopt a sustainable farming program appropriate for that community's local ecosystem. Their mission emphasizes the importance of "community-defined objectives for natural resource conservation, economic prosperity, and social equality."⁷ Joseph has generously agreed to allow me to work alongside Semilla Nueva this summer to conduct my research. Working with Semilla Nueva has a number of benefits for this project, including placement with a host family and living in a community that has already initiated its transition into sustainable farming practices. This situation will allow me to assess the impact of sustainable farming on which foods are grown, how these changes impact the nutritional status of the local population, and other health improvements that sustainable farming has facilitated, such as cleaner drinking water.

Good Spanish language skills are crucial to conduct this type of in-country research, and Semilla Nueva also assists with placement in Spanish language school in Xela. I have 2 ½ years of previous Spanish language courses, and given my current level of skill, I believe that two weeks of language study at Hermandad Educativa, the language school in Xela recommended by Semilla Nueva, will give me the language background I need to engage with the local population and conduct my research in Spanish. Upon my return to the U.S. and KUMC, I am confident these Spanish language skills will continue to be very useful, given the diversity of patients at KUMC and the growing Hispanic population in Wyandotte County.⁸

In total, I plan to spend eight weeks in Guatemala. The first two weeks will be in Xela at the language school. During my free time in these two weeks, I will also become acquainted with Semilla Nueva's organizational structure, mission, goals, farming methods and community

leadership theory. Following this intensive language study, I will move to a farming community and begin living with a *promotor* and their family. Once I am acquainted with my host family and neighboring community members, I will begin my research. As time allows, I hope to help with Semilla Nueva's sustainable farming projects as a meaningful way for me to interact with the community members, especially given how farming has shaped my career thus far.

After six weeks of living with my host family and conducting research, I will return to Kansas City to start my second year of medical school. I am hopeful this experience in Guatemala will validate my desire to devote my career to the intersection of food supply and health status.

Methods:

My specific aims are as follows:

1. To assess the impact of the Semilla Nueva sustainable farming program on the dietary habits of inhabitants of rural Guatemala, and
2. To compare the diets of communities currently engaged in sustainable farming with the diets of communities who have not yet adopted sustainable farming practices.

I will use both quantitative and qualitative research methods in this 6-week study. My sample selection will be a convenience sample of individuals who are willing to participate in the study. Although this sampling technique is prone to selection bias, it is the most efficient method to generate pilot data within the short duration of my study. Because I have not previously traveled to Guatemala, I will need a gatekeeper to link me to the community. This person will be the Semilla Nueva contact in that community, the *promotor*, whose family I will be living with for the summer.

Data collection:

First, to assess the impact of sustainable farming on food supply, I will conduct key informant interviews with 10 members of the community who have already adopted sustainable farming practices. The majority of the questions are open-ended to minimize interviewer bias. In the interviews, I will ask the following set of questions (in Spanish):

1. Could you please describe your diet before your community adopted sustainable farming?
2. Could you please describe your diet after your community adopted sustainable farming?
3. Did anything change in your eating habits? If "yes," what changed?
4. What are the crops you grow and livestock you raise?
5. Did anything change in your farming practices? If "yes," what changed?
6. Can you tell me about the impact of sustainable farming on your food security?
7. How has sustainable farming impacted your environment?
8. How has sustainable farming impacted other aspects of your health?
9. How has the adoption of sustainable farming techniques impacted you and your family?

With the permission of the key informants, I will record these interviews using my battery-powered digital tape recorder to increase the accuracy of my data collection. I will not record the names or other specific identifiers of my subjects. I will also take detailed notes during the interview (in Spanish). After the interview has concluded, I will transcribe and translate the responses into English. I will code the responses and identify emerging themes. I will not divulge

any identifying information about my subjects while reporting and disseminating my findings in my final project paper and during any oral or poster presentations.

Second, to assess the differences between diets of sustainable and traditional farming communities, I will conduct a 24-hour dietary recall⁹ interview (in Spanish) with 20 members from a sustainable farming community and 20 members from a farming community still using traditional farming practices. I will take detailed notes during these interviews (in Spanish). I will also record the gender, age, height, and weight of these individuals. After the interview has concluded, I will translate the responses to English. Then I will input this data into the MyPyramid Tracker online dietary assessment tool to assess the nutritional status of the members of each community. Following this assessment, I will calculate the percentage of individuals in each community that are meeting macronutrient and micronutrient requirements. I will assess whether the diets of the members of the sustainable agriculture community differ significantly from the diets of members of the traditional agriculture community.

When conducting all of the aforementioned research, I will take special care to obtain the consent of all participants. I will provide an informed consent document in Spanish to all participants, and I will obtain their signature to confirm their consent. A draft of this document is attached to this proposal (in English), but before my departure for Guatemala, I will check the cultural appropriateness of this document with Joseph Bornstein and the Human Subjects Committee. If my participants are unable to read Spanish, I will ask a witness to read the form to them. I will also ensure the confidentiality of my subjects. The subjects will be informed of their ability to withdraw from the study at any point in time. I will also inform the subjects of the possibility of presenting the data and findings from this project (without any individual identifiers). Prior to my departure for Guatemala, I will seek KUMC Human Subjects Committee approval through the "Exempt Review of Human Subject Research" process, as recommended by Karen Blackwell, Director of the Human Research Protection Program, upon initial review of this proposal. A draft copy of my application for exempt review is attached to this proposal. I will follow any additional instructions given by that Committee.

In developing the methodology for this research project, I have consulted several University of Kansas Medical Center faculty members, including Dr. Babalola Faseru in the Department of Preventive Medicine and Public Health and Dr. Ann Davis in the Department of Pediatrics. I am grateful for their continued expertise and mentorship. Joseph Bornstein has also been a vital resource in designing this research project, and I am grateful for his generosity and patience during these developmental stages.

Possible challenges anticipated:

I anticipate that my greatest challenge in conducting this research will be making connections with people who are willing to participate in this study. I believe the Semilla Nueva *promotor* and his or her family will provide valuable connections to other community members. I also believe that it is very important to understand and respect the cultural norms and traditions of any community in which one is a visitor. Thus, I will do my best to meet community leaders and other influential people in the community early in my stay, including members of the local health care workforce. Finally, I hope that by working alongside the farmers and their families I will

earn their trust and respect, which will create avenues for me to meet more community members willing to participate in this study.

Language is the other potential barrier I may face during the course of my research. After two weeks of intensive language study to improve my current Spanish language abilities, there will inevitably be local words for plants and foods to which I have not yet been exposed. One way I would like to address this potential language barrier before I arrive in Guatemala is to improve my Spanish listening skills by shadowing a Spanish interpreter several clinic nights at JayDoc. Hearing JayDoc patients who are also native Guatemalans speak in Spanish will expose me to words and phrases unique to Guatemalan Spanish speakers. While I am in Guatemala, if necessary, I will utilize Joseph Bornstein or other Semilla Nueva staff as a language resource.

Timeline:

May 23: Depart from Kansas City to Guatemala

May 24: Begin Spanish language classes and orientation to Semilla Nueva in Xela

June 6: Begin living with host family

June 7: Begin research in the community nearest to my host family

July 21: Return from Guatemala to Kansas City

August: Finalize data assessment, write Clendening final paper, and look for additional opportunities to present data (e.g. I would like to present at the KUMC Student Research Forum)

Budget:

This budget was developed with the help of Joseph Bornstein. It is based upon the amount Semilla Nueva asks its volunteers to estimate for their travel expenses and living expenses while in Guatemala. I will assume full responsibility for all travel costs not associated with the research project and for any unexpected costs beyond the amount of the Clendening stipend.

<u>Travel Costs</u>	
International Airfare from the USA	\$700
Taxi/Bus transport to/from airport	\$50
Travel Insurance	\$100
<u>Living Costs in Community (8 weeks)</u>	
Rent	\$120
Food	\$270
Travel (in country)	\$96
Entertainment	\$72
Moderate cell phone, Internet and Skype usage	\$96
<u>Spanish Language School</u>	
Hermanidad Educativa (two weeks)	\$300
TOTAL:	\$1804

Note:

I have a valid U.S. passport (expiration is May 7, 2014), I have recently traveled to China and Ghana, and all of my immunizations are up to date.

Attachments: Informed Consent Document Draft, Application for Exempt Review of Human Subjects Research Draft, Airfare Based on Proposed Timeline

Bibliography:

- ¹ Food and Agriculture Organization of the United Nations and World Health Organization. "Diet, Nutrition and the Prevention of Chronic Diseases." WHO Technical Report Series 916. 2003. Available online at http://whqlibdoc.who.int/trs/WHO_TRS_916.pdf.
- ² Popkin, Barry M. and Colleen M. Doak. "The Obesity Epidemic is a Worldwide Phenomenon." *Nutrition Reviews*, Vol. 56, No. 4. April 1998: 106-114. Available online at <http://www.cpc.unc.edu/projects/nutrans/publications/obes%20epidemic-NR.pdf>.
- ³ Ono, T, R. Guthold, and K. Strong. "WHO Global Comparable Estimates." Unpublished work. 2005.
- ⁴ Ruel, Marie. "Guatemala City, Guatemala: A Focus on Working Women and Childcare." International Food Policy Research Institute. (n.d.).
- ⁵ Ruel, Marie. "Guatemala City, Guatemala: A Focus on Working Women and Childcare." International Food Policy Research Institute. (n.d.).
- ⁶ Semilla Nueva. (n.d.). Semilla Nueva ("New Seed"): Growing Better Ideas, for a Better Tomorrow. Retrieved February 4, 2010, from <http://www.semillanueva.org/www.semillanueva.org/Welcome.html>.
- ⁷ Semilla Nueva. (n.d.). Semilla Nueva—Our Work: Vision + Mission. Retrieved February 9, 2010, from http://www.semillanueva.org/www.semillanueva.org/Our_Work.html.
- ⁸ Wyandotte County, Kansas Data. (n.d.). Pew Hispanic Center, a project of the Pew Research Center. Retrieved February 12, 2010, from <http://pewhispanic.org/states/?countyid=20209>.
- ⁹ Center for Nutrition Policy and Promotion. (n.d.). MyPyramid Tracker. U.S. Department of Agriculture. Retrieved February 9, 2010, from <http://www.mypyramidtracker.gov/>.

Clendening Fellowship

Department of History and Philosophy of Medicine

University of Kansas School of Medicine

February 2009

Mexico, the United States and Children's Private Healthcare

Katie McNany

School of Medicine

Class of 2013

Clendening Proposal

Introduction:

It is quite evident when you walk through the main door of the Jaydoc Free Clinic on a weekday night, the specific demographic that is in demand of healthcare. Latino immigrants are in particular need of healthcare, due to their inability to obtain insurance due to immigration status or migrant work. Approximately 10 million of the 46 million uninsured in America are immigrants, representing close to 15 percent of those without insurance.¹ "Mexico is by far the leading country of origin for U.S. immigrants, accounting for a third of all foreign-born residents and two-thirds of Latino immigrants. The U.S. is the destination for nearly all people who leave Mexico, and about one-in-ten people born there currently lives in the U.S."² Certainly with such a great influx of this population into the US, it will be necessary for all healthcare providers, particularly coordinators such as physicians, to have an intimate understanding of the culture, language and epidemiology

This project will serve as a comparison between a private children's hospital in the U.S., Children's Mercy Hospital in Kansas City, Missouri and an analogous hospital in Mexico: Hospital del Nino Poblano in Puebla, Mexico. This project will help to highlight the typical epidemiology of disease in the population in children in Puebla, Mexico in comparison with that of Kansas City, Missouri. It will furthermore detail a qualitative comparison in quality of care and ease of access for patients.

Expected differences:

- Ratio of children to Physicians is much greater in Mexico
- Quality of care approximately equal
- Technology in Hospital del Niño Poblano, although advanced for Mexico, less advanced than US care at Children's Mercy Hospital
- Insurance: Children's Mercy is semi-private, plus state-grants help cover costs, whereas in Mexico small co-pay is only requisite
- Ambience of Mexican hospital tends to be more sterile; Children's Mercy is more child-friendly

Background:

In the fall of 2007, I spent a semester abroad in Puebla, Mexico. Staying with a host family, I experienced the rich culture and warm hospitality of central Mexico. I traveled around the country, seeing the monumental cathedrals, dancing the historic dances and eating the savory cuisine. I will never forget that semester; it was monumental in focusing my life goals on serving the Latino population domestically and internationally and working in medicine as a physician.

¹ Drobnic Holan, Angie. "PolitiFact | Number of those without health insurance about 46 million." *PolitiFact | Sorting out the truth in politics*. St. Petersburg Times, 18 Aug. 2009. Web. 17 Jan. 2010. <<http://www.politifact.com/truth-o-meter/statements/2009/aug/18/barack-obama/number-those-without-health-insurance-about-46-mil/>>.

² Passel, Jeffrey, and D'Vera Cohn. "Mexican Immigrants: How Many Come? How Many Leave? -" *Pew Hispanic Center*. 29 July 2009. Web. 17 Jan. 2010. <<http://pewhispanic.org/reports/report.php?ReportID=112>>.

During my time abroad, I was also fortunate to have an internship in several Mexican hospitals in Puebla—mainly IMSS and ISSSTE. Both hospitals are government run, and provide healthcare to certain populations under government regulation. In each hospital, I had hands-on experience with the healthcare system, often able to assist in surgeries, and help cast patients. I also witnessed much bureaucracy—hierarchies of patriarchal physicians, running an old and outdated system. It reminded me of physicians of America's past—before healthcare teams and ideas of a medical home approach. Not only was the physician mentality outdated, but the technology was aged too. From basic hospital equipment—ECGs, stethoscopes or X-Ray readers—to the most powerful machines—MRIs or surgical machinery—everything seemed to be a decade or two behind its US counterparts.

This greatly contrasts my experience here in the U.S. Having shadowed at various hospitals around the country—namely Memorial Hospital in South Bend, IN, Shawnee Mission Medical Center, St. Luke's and Children's Mercy in Kansas City—I have certainly witnessed a great difference in the quality of care and overall atmospheres of the hospitals.

A recent article in National Geographic Magazine³ illustrated the huge scope of difference between Mexican and American healthcare; on average, the US spends \$7,290 annually per patient, whereas the Mexican government spends only \$823 per patient. Both a difference of available technology and healthcare infrastructure contribute to this difference. However, does this affect quality of care? Do American physicians make better diagnosticians because of the advanced technology? Alternatively, does this set them behind their Mexican peers, whose palpation and intuition may be more finely tuned without interference of instruments? During my time at Children's Mercy and in Puebla, I hope to compare physician's use of technology and other resources to compare how money is spent, and under what circumstances.

In my future career as a physician, I know with great certainty that I will travel around Latin America, to less developed countries, in order to serve that population and work towards a healthier world. I plan on participating in programs such as Doctors Without Borders, and serving the less fortunate around the world. These plans will be even easier to accomplish with my fluency in Spanish (I majored in Spanish at the University of Notre Dame), experience in travelling around the world (Mexico, Honduras, Puerto Rico, Belize and Spain), and diverse medical training at global hospitals.

Description:

This project will include two aspects: a quantitative comparison in the epidemiology between two comparable children's hospitals: Hospital del Niño Poblano in Puebla, Mexico and Children's Mercy Hospital in Kansas City, MO. There will also be a qualitative analysis of the availability and quality of care and technology available to the patients.

I chose two hospitals based on location, availability and familiarity with the sites. Kansas City and Puebla are similarly sized metropolises of about 2 million people. I volunteered briefly at the Hospital del Niño Poblano, and am familiar with a handful of doctors there. I also have some experience with Children's Mercy and I am in contact with the intern coordinator to set up this experience.

³ Andrews, Michelle. "The Cost of Care." *National Geographic Magazine* Dec. 2009: 10. Print.

Both Hospital del Niño Poblano and Children's Mercy are private hospitals and serve children regionally and nationally. They are both ranked as one of the best national children's hospitals in their respective countries.

The first month of the project will be spent at Children's Mercy Hospital in Kansas City, MO from June 1- June 25, 2010. With the help of CJ Hutto, the internship coordinator I am coordinating experiences with several doctors' groups around Children's Mercy. I will have the opportunity to see a variety of cases and work hands on alongside some of the best children's physicians in the country.

The second month of the project, June 28-July 31, I will spend in Puebla, Mexico. I will stay with the same host family that I stayed with during the fall of 2007. In the Hospital del Niño Poblano, I will work with Dr. Cortes, learning the basics of the hospital and assisting her in basic procedures.

Methods:

I will assess data regarding basic diseases, quality of care and technology based on observation and consultation with the physician. After assisting the physicians in Kansas City and Puebla, I will review each day the basic diagnoses presented by the physician, and review the prescription, treatment and available resources for the patient.

Coordinators

Lisette Monterroso: *internship coordinator for Puebla*

During my study abroad experience, Lisette served as our group's coordinator for our hospital experiences. I contacted her regarding this project, and she has put me in contact with several physicians at the Hospital del Niño Poblano

Lisette.monterroso.l@nd.edu

CJ Hutto: *director of the internship program at Children's Mercy Hospital*

CJ and I are currently discussing options for working with several physicians at Children's Mercy who would provide a similar experience to that in Puebla.

cjhutto@cmh.edu

Advisor:

Dr. Pam Shaw

Professor and Chief, Division of Ambulatory Pediatrics and Vice-Chair for Education

Doctor

Dra. Rocio Cortes

Hospitals

Hospital del Niño Poblano
<http://www.hnp.org.mx/>

Children's Mercy Hospital
<http://www.childrens-mercy.org>

Lodging

Laura Guerra Gomez: *host family*

The Guerra Gomez family has graciously offered to host me during the month of July.

Budget:

Plane Ticket Roundtrip from KC to Puebla: \$~900 (TBD based on cheapest flight at time of purchase)

Select \$588 + \$283 taxes & fees = \$871 USD per person **NO BOOKING FEES** **PRICE ASSURANCE**

Leave **Mon, Jul 5** **Continental Airlines 2794**
operated by EXPRESSJET AIRLINES INC DBA CO EXPRESS [Choose this departure](#)

 **Depart: 3:45pm** **Kansas City, MO (MCI)**
Arrive: 5:47pm **Houston, TX (IAH)**
1 stop Economy | 2hr 2min | Embraer RJ135-145 | [View seats](#)

 **Change planes. Time between flights: 0hr 33min**

 **Depart: 6:20pm** **Continental Airlines 3145**
Arrive: 8:27pm **operated by EXPRESSJET AIRLINES INC DBA CO EXPRESS**
Houston, TX (IAH)
Puebla, Mexico (PBC) Economy | 2hr 7min | Embraer RJ135-145 | [View seats](#)
Total duration: 4hr 42min

Return **Sat, Jul 31** **Continental Airlines 2129**
operated by EXPRESSJET AIRLINES INC DBA CO EXPRESS [Choose this return](#)

 **Depart: 7:45am** **Puebla, Mexico (PBC)**
Arrive: 9:58am **Houston, TX (IAH)**
1 stop Economy | 2hr 15min | Embraer RJ135-145 | [View seats](#)

 **Change planes. Time between flights: 4hr 27min**

 **Depart: 2:25pm** **Continental Airlines 2274**
Arrive: 4:17pm **operated by EXPRESSJET AIRLINES INC DBA CO EXPRESS**
Houston, TX (IAH)
Kansas City, MO (MCI) Economy | 1hr 52min | Embraer RJ135-145 | [View seats](#)
Total duration: 8hr 32min

Taxis/Public Bus Transportation within Puebla:

(Bus: \$2/day x 30 days) = \$60

(Taxi: \$40/trip x 2 trips to airport in Puebla) = \$80 (no buses go to airport)

Other Expenses

Mexican Visa/Entrance Fee: \$40

Room/Board in Puebla provided by host family (w/ \$100 donation)

Food in Mexico/KC: \$10/day x 60 days = \$600

Gas KC: ~\$60/month (drive to Children's Mercy from home)

TOTAL: \$1,940

Goals:

In the end, this summer experience would be just a stepping-stone to my future career path. As a future physician who will undoubtedly serve a very Latino population, I want to come to understand the epidemiology of the children who I will most frequently see in the clinic and at the hospital. Kansas City and Puebla are very similar cities in population and prosperity, and therefore differences in medicine and disease between the two countries should be evident.

Furthermore, working at some of the best children's hospitals in the hemisphere—Children's Mercy and Hospital del Niño Poblano—I will be exposed to the greatest quality of children's medicine available in the respective countries. Understanding this high quality of care, and noting the differences will inevitably be useful in assessing need and disparity when working with various populations. We all want to serve our patients with the highest level of care, and must work with the resources we have been given. By comparing strategies of doctoring with varying degrees of technology and resources, I will be able to hone my skills of observation and ultimately be a more practical physician.

Finally, I personally want to continue to improve my Spanish language skills. Although I majored in Spanish, I want to improve my medical diction, and learn more medical cultural differences. This experience will be highly educational and invaluable to serve my future patients.

Bibliography:

Andrews, Michelle. "The Cost of Care." *National Geographic Magazine* Dec. 2009: 10. Print.

Drobnic Holan, Angie. "PolitiFact | Number of those without health insurance about 46 million." *PolitiFact | Sorting out the truth in politics*. St. Petersburg Times, 18 Aug. 2009. Web. 17 Jan. 2010. <<http://www.politifact.com/truth-o-meter/statements/2009/aug/18/barack-obama/number-those-without-health-insurance-about-46-mil/>>.

Passel, Jeffrey, and D'Vera Cohn. "Mexican Immigrants: How Many Come? How Many Leave? -." *Pew Hispanic Center*. 29 July 2009. Web. 17 Jan. 2010. <<http://pewhispanic.org/reports/report.php?ReportID=112>>.

In the United States there are countless hospitals (both community and private), not one offering not clinical doctors, nurses, social workers, and other healthcare providers. Still, the idea of mobile medical care or "street medicine" is an important resource for much of the population in this country, and around the world. This observation signifies that there is an unmet and particularly unique need for a young physician. This observation is not at all. Most interestingly, this need is not just in the United States but in many other parts of the world.

Consequently, there are even areas where they have been tried and have failed.

My interest in mobile healthcare began when I was an undergraduate at the University of Kansas. For three years, I volunteered with Healthcare Access-Team (HAT) located on the east side of Lawrence, KS. HAT provides medical care to the underserved and uninsured residents of Douglas County. I worked as a clinical volunteer, where I managed patient records and a clinical volunteer, where I took vital signs. While organizing patient records and orders, I caught a glimpse of the work that was involved in the day-to-day work of a single person. In my given patient's chart, I found his results from another hospital, a copy results from Lawrence Memorial Hospital, or progress notes from a general practitioner. I began to

ask myself and being a "free clinic" didn't mean providing all of the services a patient may need. It was not until I began working as a gateway into the healthcare system. It is this initial patient encounter, a

series that has financial, social, emotional, and even geographic components - the patient's journey. After coming to the University of Kansas School of Medicine, I began volunteering at the Lawrence Memorial Hospital. There, I have gained a deeper insight into the needs of underserved communities. I serve as both a general volunteer and as Operations Coordinator on the clinic's Executive Board. As a member of the board, I am responsible for bringing between clinic and hospital relationships who serve our most vulnerable patients. I am also only fifteen to twenty years old, a doctor that is not. It is a right I want to give to the world. It is not just an individual's use of the healthcare system, but of a system that takes a

long, winding road from receiving the care they require.

After coming to the University of Kansas School of Medicine, I began volunteering at the Lawrence Memorial Hospital. There, I have gained a deeper insight into the needs of underserved communities. I serve as both a general volunteer and as Operations Coordinator on the clinic's Executive Board. As a member of the board, I am responsible for bringing between clinic and hospital relationships who serve our most vulnerable patients. I am also only fifteen to twenty years old, a doctor that is not. It is a right I want to give to the world. It is not just an individual's use of the healthcare system, but of a system that takes a

Introduction

In the United States, there are countless hospitals (both community and private), private practices, safety net clinics, doctors, nurses, social workers, and other healthcare providers. Still, the idea of mobile medical care, or “street medicine”, is an important resource for much of the population in this country and abroad. This observation signifies that there is an unmet and particularly unique need that is being poorly addressed, if at all. Most interestingly, there are areas of the country where mobile clinics are conspicuously absent, even areas where they have been tried and have failed.

My interest in modes of healthcare delivery outside of the mainstream began when I was an undergraduate at the University of Kansas. For three years, I volunteered with Healthcare Access Free Clinic (HAFC). Located on the east side of Lawrence, HAFC provides medical care to the underserved and uninsured residents of Douglas County. I worked as a clerical volunteer, where I managed patient records, and a clinical volunteer, where I took patient histories and vital signs. While organizing progress notes, labs and orders, I caught a glimpse into the spectrum of cooperation that was involved in the care of a single person. In any given patient’s chart, I might have found lab results from another free clinic, X-ray results from Lawrence Memorial Hospital, or progress notes from a generous cardiologist. I began to understand that being a “free clinic” didn’t mean providing all of the services a patient may need at no cost; rather, it meant serving as a gateway into the healthcare *system*. It is this initial barrier to access – a barrier that has financial, social, temporal, cultural, and even geographic components – that prevents many individuals from receiving the care they require.

After coming to the University of Kansas School of Medicine, I began volunteering at JayDoc Free Clinic. There, I have gained a deeper insight into the needs of indigent communities. I serve as both a general volunteer and as Operations Coordinator on the clinic’s Executive Board. As a member of the Board, I am responsible for triaging between thirty and forty individuals who arrive each night, hoping to be seen. Of these, only fifteen to twenty will see a doctor that night. Each night, I work to decide which of the thirty or so individuals has a) the most urgent need, and b) a requirement that JayDoc’s limited

resources can adequately address. Over the past few months, I have spoken to hundreds of people and have had the enlightening experience of listening to their stories. Many patients come to JayDoc because they are illegal immigrants, and the clinic is one of the few resources that does not ask for documentation. Some come because the clinic is truly free, and does not require proof of income. Finally, JayDoc is the only after-hours walk-in clinic, and thus receives people from all over Kansas and Missouri – sometimes from hours away – that have pressing medical needs. It is incredibly rewarding to participate in an organization that fills a gap in the current medical system. Still, my conversations with patients each night have shown me that there are systemic flaws that that JayDoc cannot compensate for. I sometimes leave wondering how many people could not make the drive to downtown Kansas City, or did not have the bus fare the night they got sick, or could not access the clinic's website and learn that we would not turn them away for not having documentation.

My experiences in free clinics bring up questions that I do not believe the medical and public health fields have fully answered. In fact, I do not believe the answers are currently being sought, except by individuals. In a profession that rightfully prides itself on reaching out to the fringes of society, it is still possible for many to be overlooked. Perhaps, with mobile medical clinics, there is a budding solution.

Background

There are 329 members of the Mobile Health Clinic Network¹, a national organization aimed at fostering communication and cooperation between different mobile health agencies around the country. Of these, there are a number of universities, hospitals, and health partnerships who do not directly provide street medicine, but instead serve as partners in mobile health efforts. Thus, it is plain that there are very few true mobile medical services, particularly in comparison with the 5,815 hospitals in the United States².

It is evident that there is a need for mobile health resources, yet there is not the kind of overwhelming demand that initiates changes in public policy, stimulates advocacy for the patient population, or promotes incentives for professionals to donate their time. This can partially be explained by the extremely low socioeconomic status of and poor advocacy for the primary recipients of mobile healthcare services, particularly the homeless³. The homeless population is mobile and reticent in trusting healthcare providers. In addition, many individuals of lower socioeconomic status do not have the time or resources to seek out medical care. This is a conflict because most current resources follow the paradigm of being static central locations that patients willingly seek out. In order to overcome these challenges, providers must be flexible, equally mobile, and willing to search out their patient population⁴.

Goals

This summer, I would like to explore the structure and implementation of mobile healthcare. There are many mobile medical clinics around the country. I would like to visit several of them to explore the conditions in each community that require a mobile clinic, as opposed to other forms of healthcare. In addition to gaining a broader understanding of what a mobile clinic is and how it functions, I would like to explore the circumstances that led area healthcare professionals to decide that a mobile clinic would best serve the needs of the community. I believe I could accomplish this by volunteering at each clinic for 2-3 days, as well as meeting with some of the clinic's leaders. Finally, I'd like to examine how communities respond to the presence of mobile clinics. I think this could be accomplished by designing a short survey for the patients I encounter.

First, I would like to visit the Kids Mobile Medical Clinic (KMMC) through Georgetown University Hospital in Washington, DC. The KMMC is a comprehensive pediatric unit that aims to provide a primary care medical home to more than 42,000 children. Next, I plan to shadow the Huguley Mobile Health Services Bus in Burleson, TX. The Huguley Bus offers a variety of services focused on general medical care and physical examinations. For example, the clinic offers physicals, immunizations,

and a variety of screenings for chronic conditions. Finally, I hope to visit St. Joseph Regional Medical Center's Mobile Medical Unit in Mishawaka, IN. I have received a positive response from the medical unit, and am currently waiting on their lawyer to draft an agreement permitting me to visit. Based on my conversations with the clinic's leadership, I do not anticipate this to be an obstacle.

For the second portion of my project, I would like to examine the relationship between clinics abroad and our state medical system in Kansas. I am focusing on two areas: the resources currently available to patients with limited access to care – with a specific focus on rural communities – and the potential value of mobile health clinics in addressing poor access. With regard to my first goal, I will be serving as Executive Director of JayDoc Free Clinic in Kansas City, KS. This is a continuous commitment that will require not only fulfilling all of the administrative duties surrounding the clinic's operation and growth, but also working at least one full night each week. To focus my efforts further, I will visit the Guadalupe Clinic in Wichita, KS. The Guadalupe Clinic provides basic medical care and specialist referrals to uninsured patients below the poverty line. I plan on interviewing the physicians and staff to discover their attitudes on providing care to their local population, as well as to those patients that come from more rural areas. Furthermore, I am meeting with Dr. Michael Kennedy, a prominent rural health resource, and Jenna Kennedy, a fellow medical student and rural resident, to identify other clinics that would be useful to visit.

Overall, I hope to gain a better understanding of how healthcare providers help patients overcome the multiple obstacles to accessing quality care and the role – real or potential – of mobile medical clinics in this process.

Logistics

I plan to spend three days with each clinic. In Washington, I will stay with my cousin, and thus not incur any costs. In Burleson and Indiana, I will need to rent a hotel room (I am currently speaking with family friends about places to stay near Mishawaka, which would eliminate the housing cost there.)

I plan to fly to each location, except those within Kansas, which are within driving distance. I will use public transportation in Washington, and rent a car in Burleson and Mishawaka. I hope to do most of my out-of-state traveling in late May and June, and travel to multiple clinics in Kansas during July. While in Kansas, I will not have to use Fellowship funds for food or housing, as those are already accounted for in my personal expenses. I plan to absorb any expenses I may incur outside of the Clendening Fellowship.

Timeline

- JayDoc Free Clinic Continuous, 1/week
- Kids Mobile Medical Clinic: May 25 – 29
- Huguley Mobile Health Services Bus: June 1 – 5
- St. Joseph Regional Health Center Mobile Medical Unit: June 8 – 12
- Guadalupe Clinic: July 7 – 9

Budget

• Travel Expenses	
○ Washington, DC	\$228 (airfare)
○ Burleson, TX	\$513 = airfare + hotel + car
○ Mishawaka, IN	\$702.14 = \$495 (airfare and hotel) + \$207.14 (car) ¹
• Food	\$500 = \$25 / day; 20 days abroad
• Gas and Transportation	\$200
<hr/>	
Total	\$2,143.14

¹ In the event that this portion of the trip needs to be canceled, the total would then be \$1,440.97.

Contacts

- Kids Mobile Medical Clinic

Dr. Matthew Levy, Medical Director of Community Pediatrics

- Huguley

Joyce Melius, Student Coordinator

- St. Joseph

Michelle Peters, Director of Outreach Services

- Guadalupe Clinic

Faculty Advisors

- Dr. Allen Greiner

Department of Family Medicine

- Dr. Frederick Holmes

Department of History and Philosophy of Medicine

References

¹ <http://www.mobilehealthclinicsnetwork.org/>

² <http://www.aha.org/aha/resource-center/Statistics-and-Studies/fast-facts.html>

³ Romeo, June Hart. Down and Out in New York City: A Participant-Observation Study of the Poor and Marginalized. *Journal of Cultural Diversity* 2005;12(4):152-160.

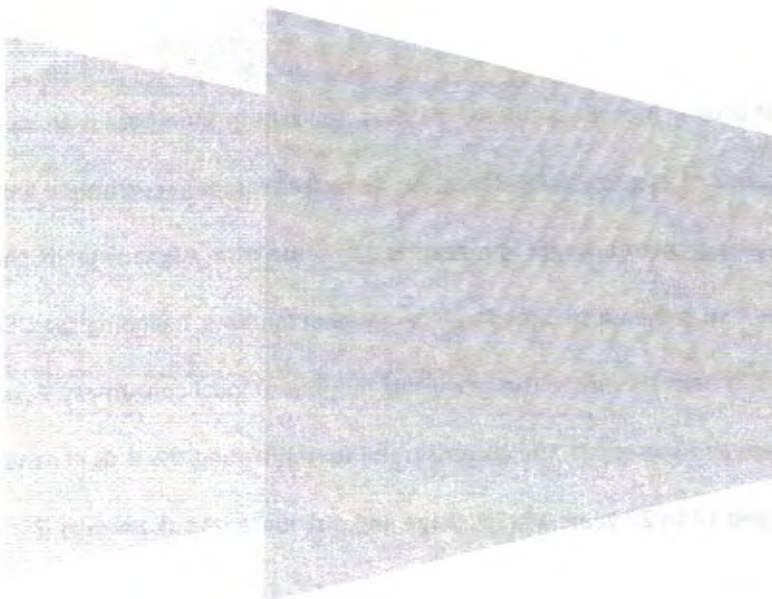
⁴ Howe EC, Buck DS, Withers J. Delivering Health Care on the Streets: Challenges and Opportunities for Quality Management. *Quality Management in Health Care* 2009;18(4):239-246.

^v All flight, rental car, and hotel information obtained through www.cheaptickets.com

A Clendening Summer Fellowship Proposal

The Determinants of Health: Heroin Addiction among Youth in Mombasa, Kenya

Zahra Shirazy



INTRODUCTION

Objective

One of the first lessons that I have learned in medical school is that a person's health status is not just a consequence of the disruption of an individual's biological construct, but that there can also be other factors involved:

- The individual's behavior
- The social and economic environment
- The physical environment
- Access to quality health care
- Policies and interventions

The factors listed above are the constituents of the Determinants of Health Model, which is a theoretical construct used to describe the health of individuals or populations (Delzell, 2009). My goal for this project is to develop a comprehensive understanding of the factors that are associated with heroin addiction among youth in Mombasa, Kenya, by using the Determinants of Health Model as a guideline. I am originally from Mombasa, and this subject matter has me very concerned about the young people in my hometown and their future.

BACKGROUND

Heroin use in Mombasa

Heroin has been used as a street drug in Mombasa since the 1980s. The port in Mombasa is an ideal drug trafficking center both because of its geographical location, as well as rampant corruption among government officials. The drug consignment brought in is reported to come from Afghanistan (Ochami, 2009) and Pakistan (Allen, 2006), and is then distributed to international markets, including the USA. However, a substantial amount still finds its way to the increasing number of local consumers. According to a report in *The Standard*, a Kenyan newspaper, the current trend for infiltrating the drugs to the local market is by using young boys aged 12 to 20 years who package and distribute it to the clients (Mudi,

2009). The heroin is packed in 1 g sachets and each is sold for Ksh.200, which is equivalent to \$2.60. The boys then carry the drugs in school bags and peddle their merchandise at the nearby schools and at other locations.

The easy access to the heroin encourages its use, which leads to the increased problem of addiction and deaths due to overdosing. Furthermore because of the transition from "brown sugar", which is consumed by inhalation, to "white crest", a water soluble version of heroin that is injected intravenously, there are secondary problems that heroin addicts face: HIV and Hepatitis C (Beckerleg, 2006).

Development of interest

Although the heroin addiction problem has been going on for decades, I was not cognizant of the gravity of the situation until I came across an article in one of the Kenyan newspapers in 2005. What I read unsettled me: I was both saddened by the situation and ashamed by my oblivion. I believed then and still do now that an already burdened third world country having to deal with this kind of problem is senseless, because this is a problem that can be prevented. I felt compelled to follow up on what I had read, and so a few months later when I went to Kenya, I asked the Medical Director at the Coast General Public Hospital about the issue. She directed me to Dr. Mumba, a then attending physician at the hospital who happened to work with some of the rehabilitation centers. Prior to my departure from Kenya, Dr. Mumba took me to one of the inpatient rehabilitation centers located in the South Coast, and also took me to one of the outpatient community based centers that was located within Mombasa. The visits to these centers afforded me the opportunity to witness that there was indeed a problem and that something needed to be done about it.

I wanted to contribute somehow to help combat this problem and I thought I could do so by trying to mobilize any kind of resources that would be beneficial from the US to Kenya. I first thought of the

research community and since I was living in Philadelphia at the time, I set up a meeting with Dr. David Metzger, a researcher at the University of Pennsylvania department of psychiatry, and his research interests were in HIV prevention interventions among drug users. He asked me to get more details about what kind of assistance is needed in Kenya, but I was unable to re-establish communication with Dr. Mumba, and then I moved to Wichita to continue my education. I therefore wasn't able to do anything then. However, with the Clendening fellowship sponsorship, I will have the opportunity to go back to Kenya and gather information that I hope can be used to initiate larger scale projects that would help deescalate this growing drug problem.

DESCRIPTION OF METHODS

Outreach worker training and volunteering

I would like to take a hands-on approach to my project and thus my plan is to work with the Teens Watch Center, a drug rehabilitation center for youth. In addition to rehabilitation services the center runs an outreach program, which entails outreach workers going into the community to educate the youth about substance abuse and its relation to HIV. Part of my project involves training and volunteering as an outreach worker. As an outreach worker I will be able to go to venues such as schools, churches and mosques and offer "health talks", which are informational sessions about substance abuse, HIV and STDs, and behavioral modifications. The volunteering sessions will not just be a way for me to offer my services to the community, but will also create an avenue through which I can recruit community members for my interviews.

Shadow a psychiatrist

I will also be spending some time with Dr. Mwangome, a psychiatrist who treats addicts, to learn about the medical treatment that is implemented. I will be observing him in both inpatient and outpatient settings.

Interviews

I have composed a list of questions based on the Determinants of Health Model that I will use to conduct interviews with. I intend to interview the residents at the Teens Watch Center, the program coordinator Mr. Cosmas Maina, Dr. Mwangome, and members of the community. Demographic information will be collected for the drug users only. The interviews will be recorded. Interviews will be conducted in English since English is the official language. My native language is Swahili, which is the national language, and I will be able to translate the questions in Swahili should the need arise. The exact number of drug users to be interviewed will be determined when I am at the Teens Watch Center. The subjects' willingness to participate as well as their parents consenting will determine the sample size. Also the interview is lengthy and this might keep the sample size small. Each interview is expected to last about thirty minutes. A pretest will be conducted to ensure that the interview questions are valid and that the allocated time is sufficient. See appendix to view parental consent form and interview questions.

Research Permit

I have tried to call the Ministry of Health in Kenya using the number listed on their website to inquire whether I would need a special permit in order to conduct my project, but have not been able to get through after calling several times. I also tried calling the Kenyan Embassy in Washington DC, but their office seems to be constantly closed even when I call during the working hours the website and the automated voice recording conveyed. From my experience living in Kenya, dealing with government related matters is done best in person.

Timeline

Date (Year: 2010)	Event
May 17 th	Traveling from Wichita to Mombasa
May 24 th – June 4 th	Outreach worker training
June 7 th – July 23 rd	-Volunteer as an outreach worker and conduct interviews: 4 days/ week -Shadow Psychiatrist: 1 day/ week
July 30 th	Travelling from Mombasa to Wichita

Data analysis

A qualitative analysis of the information gathered from the interviews, as well as notes taken during each outreach and shadowing session will be conducted to elicit the factors that influence the development of heroin addiction among youth in Mombasa. Each factor will be itemized based on the categories listed by the Determinants of Health Model. A distinction will also be made between factors that have a positive influence versus those that have a negative influence. Data will be kept in a safe place and only I and individuals pertinent to the analysis of the records will have access to the data.

LOGISTICS**Travel advisory issue**

I have spoken to Ms. Judith Reagan about going to Kenya, which is one of the countries that KUMC students cannot go to because it is on the travel advisory list, and she stated that I am exempted from the rule because I am going home. Should I be selected as a Fellow I will be meeting with Ms. Judith to fill out the required paperwork

Access

I will be flying from Wichita, KS to Nairobi then to Mombasa. In Mombasa, public transportation is easily accessible to commute within the town. During the first two weeks I will be staying at the rehabilitation center which is located in Diani, just outside Mombasa. After the training I will be staying with my family

in Mombasa since the sites I will be volunteering at and the Psychiatrist are in Mombasa. I will be commuting to Diani using public transportation during the days interviews are scheduled.

Contacts

Zahra Shirazy
SOM2013

Dr. C. M. Mwangome
Psychiatrist
Coast Province General Hospital

Mr. Cosmas Maina
Program Coordinator
Teens Watch Center

BUDGET

Item	Cost
Plane ticket : Wichita-Nairobi-Mombasa(Round trip)	\$1700
Visa (because I use my American passport)	\$25
Local public transportation	\$25
Accommodation at the Teen Center for 2 weeks	\$60
Sim Cards for cell phone for 8 weeks	\$30
Internet connection for laptop for 8 weeks	\$ 60
Printing Cost for demographic questionnaire and parental consent	\$30
Books to donate to center	\$70
Total	\$2000

I'll be living with my family after the training and therefore food and housing will be taken care of. if needed, any expenditure beyond the \$2000 will be supplemented by what I have saved from my Financial Aid.

BIBLIOGRAPHY

- Allen, K. (2006, May 9). Traffickers' drugs haven in Kenya. *BBC News*. Retrieved from <http://news.bbc.co.uk/2/hi/africa/4753377.stm>
- Beckerleg, S., Deveau, C., & Levine, B. (2006). Heroin use in Kenya and Findings from a Community Based Outreach Program to reduce the spread of HIV/AIDS. *African Journal of Drug & Alcohol Studies*, 5, 95-107.
- Beckerleg, S., Telfer, M., & Lewando, H.G. (2005). The rise of injecting drug use in East Africa: A Case Study from Kenya. *Harm Reduction Journal*, 2 (12). Retrieved from <http://www.harmreductionjournal.com/content/pdf/1477-7517-2-12.pdf>
- Beckerleg, S., Telfer, M., & Sadiq, A. (2006). A Rapid Assessment of Heroin use in Mombasa, Kenya. *Substance Use and Misuse*, 41, 1029-1044
- Delzell, J. (2009). The Determinants of Health. Class Lecture. University of Kansas School of Medicine, Kansas City, KS.
- Mudi, M. (2009, March 6). How police abet drug trafficking in Coast. *The Standard*. Retrieved from <http://www.standardmedia.co.ke/InsidePage.php?id=1144015798&catid=459&a=1>
- National Agency for the Campaign against Drug Abuse Authority. Retrieved from <http://www.nacada.go.ke/htm/about.html>
- Ochami, D. (2009, December 14). Drug Barons storm Kenya. *The Standard*. Retrieved from <http://www.standardmedia.co.ke/InsidePage.php?id=1144030365&cid=4>
- Parental Consent form format. Retrieved from <http://lpsl.coe.uga.edu/Projects/AAlaptop/MEMBERS/instrument/Parent=StudentConsent.pdfTeens>
- Watch Center. Information about the center. Retrieved from <http://teenswatch.webatu.com/index.php>
- World Health Organization. The determinants of health. Retrieved from <http://www.who.int/hia/evidence/doh/en/>

APPENDIX I

Parental Consent

I give my consent for my child _____ to be interviewed for approximately 30 minutes for a project titled: "The Determinants of Health: Heroin Addiction among Youth in Mombasa", which is being conducted by Zahra Shirazy, a first year medical student from the University of Kansas Medical Center. I understand that this participation is entirely voluntary; I or my child can withdraw consent at any time without penalty and have the information, to the extent that it can be identified as my child's, returned to me, removed from the records, or destroyed.

1. The reason for the project is to understand what factors influence the occurrence of heroin addiction among youth in Mombasa.
2. The interview will involve questions about my child's behavior, social and economic environment, and access to health care
3. No physical discomforts foreseen, though questions may be emotionally taxing
4. No risks are foreseen
5. The results of this participation will be confidential, and will not be released in any individually identifiable form without the prior consent of myself and my child
6. The interviewer will answer any further questions about the project, now or during the course of the project, and can be reached by phone at (a Kenyan cell phone number will be provided)

Please sign both copies of this form. Keep one and return the other to the investigators.

Signature of interviewer

Signature of Parent/Guardian

Date

APPENDIX II

Demographic questionnaire (Please circle the appropriate choice)

What is your age?

What is your gender?

Female

Male

Are you currently in school?

Yes

No

If you are currently in school what level are you in?

Primary School

Secondary School

College/University

If you are currently NOT in school what level did you reach?

Primary school

Secondary School

College/University

Do you or did you go to a private or public school?

Private

Public

Appendix III

Interview questions for the drug users

The individual's characteristics and behaviors.

Are you here at the rehabilitation center because you want to or were you forced to be here?

What age did you start using?

How long have you been using?

Why did you start using heroin?

Are you still using heroin?

Do you use heroin to self medicate?

Do you use other drugs other than heroin?

Do you drink alcohol?

Do you have any medical problems?

Do you have any psychological problems?

The social and economic environment

Do any members of your family use heroin?

Do any of your friends use heroin?

Where do you get the money to buy the heroin from?

What is your religion and do you follow your religions teachings?

The physical environment

Do you have any concerns (safety, pollution, etc) about where you live?

Do you have any concerns (safety, pollution, etc) about where you go to school?

Access to quality health care

Can your parents afford for you to see a doctor whenever you have a medical problem?

Is it easy or difficult for you to get to the rehabilitation center?

Additional Comments

Appendix IV

Interview questions for psychiatrist, rehabilitation center administrator, and members of the community.

Access to quality health care

Are there enough resources to cater to those seeking treatment?

Policies and interventions

What policies and or interventions have been implemented by:

The healthcare providers?

The government?

The schools?

The community?

Additional Comments