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Comparison of Early Education for Children with Disabilities in Peru and Kansas

Erin Atwood

University of Kansas School of Medicine

Clendening Fellowship Proposal

February 17th, 2014

INTRODUCTION: In the United States, we have federally and state funded programs that provide services to infants and toddlers 0-3 years of age with disabilities and their families. Through the provisions of Part C of the Individuals with Disabilities Education Act (IDEA), each family is entitled to receive some sort of early intervention therapy or education in the hopes of improving the child's physical, cognitive and social abilities. In Peru, programs like these are rare because the government does not provide special services or extra funding for families to help support their children's growth and development. With the support of the Clendening Fellowship, I plan to compare the differences between the early intervention education programs available in Kansas and those available in Peru. I will also analyze the attitudes and perceptions of parents about the importance of these programs in the development of their child and their knowledge about services that are available in their respective areas. I plan to observe several organizations in Kansas that provide services for children ages 0-3 years old including tiny-k, a Part C Early Intervention Program in Kansas, the Center for Child Health and Development at KUMC and the Down Syndrome Guild of Greater Kansas City. In Peru, I will observe and collect information from Centro Ann Sullivan del Perú (CASP) in Lima which has an early education program for children with different abilities ages 0-3 years old.

BACKGROUND: I was first introduced to CASP as a junior in college when I studied abroad in Lima. Centro Ann Sullivan del Perú is a pioneering institution that implemented one of the first curriculums for working with people with different abilities in South America. The program has developed substantially since Liliana Mayo, the founder and director of CASP, started the program out of her parent's garage in 1979. When I studied abroad in 2011 in Lima, I spent time volunteering in the classrooms at CASP and noticed the program's unique family-driven approach to working with children and adults with different abilities. After returning to Kansas from my short time abroad, I knew I wanted to return to Lima and CASP so I applied for and received a Fulbright Research Grant. As a result, I spent ten months last year in Peru studying the behavioral and communication development of children ages 3-6 that had certain previously-identified behaviors and characteristics.

While at CASP last year, I watched the early education program grow and expand. A group of physical and occupational therapists from Kansas came to Lima twice during my stay there to help transform the program so it could provide all-encompassing services to the children and families that attended the weekly classes. Through my involvement with CASP and these therapists, I learned about the expansive structural and ideological aspects that go into creating a program designed to support the motor, self-help, communication, social-emotional and cognitive development of the children as well as support the families as they struggle to help their child with limited resources. I was constantly amazed by the dedication of the staff at CASP and the families that went above and beyond for their children.

Upon returning to Kansas, I have remained in communication with the staff at CASP and have followed the development of the early education program and was able to return this fall to contribute as an interpreter for this Kansas group of therapists in the early education classroom. Services and supports to infants and toddlers and their families at CASP occur primarily at the center with parents accompanying their child to CASP for weekly sessions. Comparing it to programs I have learned about here, I am curious about the similarities and differences between the early intervention programs that the U.S. provides and the early childhood program that CASP provides. I have shadowed at the Center for Child Health and Development at KUMC and I was impressed by the team-driven focus that involved specialists from a variety of fields who collaborate in order to provide services to children from the surrounding area. I have also observed appointments with a physical therapist from tiny-k, a program

that provides services in the natural environment which typically means the homes and child care environments of the infants and toddlers. I have been exposed to the Down Syndrome Guild in Topeka, but I would like to learn about the resources and services the organization in Kansas City provides for parents.

Since high school, I have been working with children with developmental disabilities such as Down syndrome and Autism, and my passion for working with this population grew during my year spent at CASP. I hope to pursue a specialty in Pediatrics, so this project is interesting to me because eventually I will be working with programs like these in Kansas. I believe it is important to be aware of the strengths of each program and understand the different services that are available. Furthermore, CASP has such a unique and successful program, I think we have much to learn from their example. I hope to integrate some of their philosophies and curriculum into my future career as a pediatrician.

DESCRIPTION: My goal with this project is two-fold: firstly, I want to compare the basic structural and organizational differences between the Kansas programs and the program at CASP. In order to do this, I will collect brochures and pamphlets that are given to families as well as meet with a few staff members from each location in order to understand the referral process, general clinic or program set up, and the different services that are offered. Secondly, I will analyze parental knowledge of services available to families and evaluate the importance of these services to parents. Pending requisite approvals from each organization, I plan to observe five children's appointments at each program and interview and survey the parents after such appointment (if the parent consents). (Survey attached in Appendix I).

In Kansas, I have specifically chosen a variety of programs in order to demonstrate the array of options available in our state. Tiny-k is a federally and state-funded program that provides services at no cost to any eligible infant or toddler with developmental delays or disabilities. This particular tiny-k program I plan to observe consists of a teacher, dietician, physical, occupational and speech therapists and psychologist who collaborate together to provide services through in-home visits. The CCHD clinic at KUMC is a specialized clinic that offers a variety of programs such as medical consults, therapy, evaluations and social skills and behavioral support. Patients are often referred by their physician to the CCHD, although some parents seek out the services on their own. This organization works with a variety of professionals, including physicians, psychiatrists, social workers and speech, occupational and physical therapists. The Down Syndrome Guild is a non-profit and family-centered program that focuses on education and support of the entire family unit. It is run primarily by volunteers.

CASP is a privately-funded organization that offers services to students on a sliding scale or free of charge, depending on each family's economic situation. There are expectations and requirements for parents, siblings and grandparents to follow while their child is enrolled as a student at CASP. The classroom setting includes a teacher, a physical therapist and at least one parent of each child. There is also an in-home training component where the teacher visits the family in order to evaluate how the lessons from the classroom are being incorporated into their daily lives.

At the CCHD clinic, I will observe five separate appointments and then interview the parents directly afterward. I would like to observe a variety of interactions, including, to the extent possible, a one-on-one therapy session, a team meeting, an initial evaluation and a session in a preschool or classroom setting.

With tiny-k, I plan to travel with the team members to five separate appointments in family's homes. I will observe appointments where two team members collaborate together to provide an initial evaluation of a child and also a few appointments where the professional coaches the family on strategies and techniques to use every day to enhance the development of their child. These appointments can vary in location so it will be important for me to coordinate in advance in order to allow adequate driving time and preparation for each appointment. I have my own car so transportation issues will be minimal. I also plan to observe at least one of the team meetings that are held regularly throughout each month.

With the Down Syndrome Guild of Greater Kansas City, I plan to attend fundraisers, support groups, training events or general information sessions whenever possible throughout the summer. This will be more of an informal setting, so the parent interviews will be the most informative and significant aspect within this setting.

Timeline:

Early/mid-March: Submit parent survey to IRB for approval

May 26th-June 6th: Attend parent meetings/trainings, any special events through Down Syndrome Guild of Greater Kansas City (The summer calendar is not fully updated yet)

June 10th: Fly from Kansas City to Lima, Peru

June 11th-June 20th: Observe and collect data from CASP

June 21st: Return to Kansas

June 23rd-July 3rd: Observe and collect data from Tiny-K

July 7th-July 25th: Observe and collect data in CCHD Clinic

July: Begin write-up of observations and comparisons of survey results

Total length of project: 8 weeks

*In order to maximize the number of events and appointments I am able to observe, I may end up observing at each location throughout the entire summer as opposed to a specific two-week time span, depending on the availability of patient appointments.

METHODS: I have spoken with Ellen Pope, a clinical assistant professor in the Department of Occupational Therapy Education at KUMC, and she has agreed to serve as a mentor throughout my project. She has been involved in the early childhood program development at CASP, was previously the director for one of the tiny-k networks in Kansas and has served with organizations that provide services for infants birth to three both in Kansas and New Mexico. She has been helpful in reviewing my project proposal and she also plans to help me with the development of the parent survey. (See letter of support in Appendix II).

I plan to observe and collect data from each program for about two weeks. In Kansas, my goal is to observe 5 family appointments or other services at each clinic and conduct a family interview after each observation.

CCHD Clinic: I have spoken with Dr. Chet Johnson and shared my proposal with him and he is supportive of me observing patients at the Center for Child Health and Development (CCHD) at KUMC. (See email below in Appendix II).

Tiny-K: Because tiny-k goes into homes in Northeast Kansas, I plan to observe several home visits where the team members work together. I have spoken with Rachel Raydo, the co-director of Northeast Kansas Infant Toddler Services (Tiny-k) and she has offered her support for the project. (See email below in Appendix II).

Down Syndrome Guild of Greater Kansas City: While the complete summer calendar has not yet been posted for this organization, I have met with the director, Amy Allison, and she has agreed to help facilitate observations of support groups, trainings and conferences and interviewing a few of the families. (See email below in Appendix II).

Centro Ann Sullivan del Perú in Lima: The early education classes take place every Monday and Wednesday at CASP, so I plan to observe two Wednesday sessions and one Monday session. In the times outside of the actual classes, I will conduct parent interviews and collect information about the structure of the classes from the CASP personnel. I am fluent in Spanish so I will be able to converse with families directly. Liliana Mayo, the director of the Ann Sullivan Center, is supportive of my idea and eager to see a research project focused on the development of the early education program at CASP. (See email below in Appendix II).

While in Lima, I plan to stay with the same host family that I lived with while I conducted my research last year. I am very close with this family and they have given me permission to stay in their home. I would pay the same amount as last year, \$20 per day, which includes two meals a day and my own personal bedroom. The other \$10 listed below in the budget for room and board accounts for any other meals outside of the home.

BUDGET:

Round-Trip Airfare to Lima, Peru	\$1200.00
Room and Board in Lima, Peru (\$30 per day with host family)	\$300.00
Miscellaneous Expenses in Peru (food, taxi transportation)	\$300.00
Gas for Observation Days with Tiny-K	\$200.00
<u>Rent in Kansas City for June/July:</u>	<u>\$500.00</u>
Total:	\$2500.00

*I understand that any expenses over the \$2500 will be my responsibility and I have planned accordingly.

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Center for Child Health and Development: <http://www.kumc.edu/school-of-medicine/cchd.html>

Centro Ann Sullivan del Peru: <http://en.annsullivanperu.org/>

Children's TLC: <https://www.childrenstlc.org/index.html>

Down Syndrome Guild of Greater Kansas City:

http://www.kcdsg.org/index.php?cur_date=1398920400

Tiny-K: <http://www.ksits.org/>

IDEA-U.S. Department of Education: <http://idea.ed.gov/part-c/search/new>

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APPENDIX I:

Parent Survey

Demographics:

DOB of child:

Gender:

Language (circle): English Spanish

Diagnosis:

When did your child receive the diagnosis?

Location Observed: (circle one)

Tiny-k CCHD KCDSG CASP

Questions

1. How often does your child receive services?
 - a. What services/therapies are included?
 - b. Where are the services provided?
2. When did your child start receiving services? (Any sort of services, not necessarily with the program where the child is receiving services currently)
3. How did you seek out/come into contact with this organization?
4. What is your understanding of the philosophy of this organization?
5. What made you seek out support services so early on?
6. What did you know about your child's diagnosis before coming to this program?
7. Did you consider other alternatives? If so, what other options did you consider or actually participate in?
8. What is the most important skill or aspect that you as the parent hope to gain from these services?
9. What is the most important skill or aspect you hope that your child will gain from these services?
10. What are you most concerned about in terms of your child's growth and development now and in the future?

11. What is the greatest benefit of you and your child receiving these services and supports?
12. What features of the program that you are currently involved with are most important to you?
(Please number from 1-7, 1 being most important, what has made the most difference to you)
 - a. Classroom sessions with teachers/therapists
 - b. Home visits
 - c. Parent information (books/handouts, verbal, videos, websites, etc.)
 - d. Developmental information (books/handouts, verbal, videos, websites, etc.)
 - e. Interaction with other parents
 - f. Journaling
 - g. Coordination with other services and supports including referrals to specialists
13. What is your role as the parent in this program?
14. Will you continue to seek services for your child after this class/therapy/program ends?
 - a. How long can your child continue with the current institution/organization where he or she is currently receiving services? If the organization stops providing services at a certain age, do you know what will be the next step?

Pain in Perspective: A Qualitative Study of Chronic Pain Patients' Experience with Pain and Pain Management

Clendening Summer Fellowship Proposal

Joel Burnett

University of Kansas, School of Medicine, Class of 2017

February 17, 2014

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Introduction:

With approximately 100 million adults affected, chronic pain represents a national crisis of public health. Unfortunately, there are no easy solutions. Treating chronic pain is a complex task and the barriers to effective treatment are numerous. Among those barriers is the marginalization of the patient's perspective in the management and treatment of chronic pain. For instance, practitioners frequently adopt attitudes and goals that are different from those of their patients living with chronic pain (Frantsve and Kerns 2007), and practitioners often encourage patients to describe their experience with chronic pain only briefly, rather than present a narrative that fully explains the impact of pain on their lives (Morris 2002). Patients report that these experiences leave them with the feeling that their pain is trivial or, worse, illegitimate (IOM 2011). The aim of this study is to gain an understanding of the impact that chronic pain has on patients' lives by providing a context in which they may give voice to their personal narratives. Through qualitative interviews with chronic pain patients in Kansas City, I aim to gain an understanding of these patients' perspectives, their struggles with pain, and their efforts to manage chronic illness. The results and analysis of these interviews will be provided to local organizers of the PAINS project, an initiative of the Center for Practical Bioethics, to help them in their efforts to foster better understanding between practitioners and chronic pain patients.

Background:

In 2011, the Institute of Medicine published a seminal report concerning pain in the United States. *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research* (2011) revealed that acute and chronic pain represent nothing short of a national crisis of public health.

The scale of the problem is alarming. Chronic pain alone affects approximately 100 million Americans at a cost of \$560-635 billion annually. But the crisis of chronic pain is also complex: it is colored by under-treatment and under-diagnosis, substantial disparities in treatment and management of chronic pain, and social stigma.

Among the barriers to improved treatment of chronic pain is the marginalization of the patient's perspective in the management and treatment of chronic pain. People with chronic pain, especially women, have been shown to often have attitudes and goals that are at odds with the attitudes and goals of providers; while patients seek to have their pain legitimized, providers focus on therapy (Frantsve and Kerns 2007). Additionally, researchers working with patient focus groups have noted "perceived failures of providers to fully respect, trust, and accept the patient, to offer positive feedback and support, and to believe the patient's reports of the severity and adverse effects of their pain" (Upshur et al. 2010). Others have noted that "patients are encouraged to describe their experience only briefly and in terms most familiar to physicians, rather than present a narrative that fully explains the impact of pain in their lives" (Morris 2002). Finally, consumers who testified before the IOM committee reported that patients often believe practitioners trivialize pain, which makes patients feel worse (IOM 2011, pp. 154).

The marginalization of the patient's perspective in the treatment of chronic pain is lamentable. But it also represents a barrier to treatment. To overcome this barrier, we must begin to appreciate with greater clarity the extent to which chronic pain burdens and disrupts patients' lives. By listening to patients' perspective, we may foster better understanding between practitioners and patients and thereby reduce under-treatment, under-diagnosis, and disparities in the treatment and management of chronic pain.

With the Clendening Summer Fellowship, I aim to gain insight into chronic pain patients' experience of living with chronic pain. In the clinic, the narratives of patients with chronic pain are, for various reasons, cut short. Through interviews, I propose to provide a context in which these patients may give voice to their narratives. Each interview will be documented and, through quantitative methods, I will analyze the patients' narratives and descriptions. The analysis of these interviews will be provided to local organizers of the PAINS project, an initiative of the Center for Practical Bioethics, to help them in their efforts to foster better understanding between practitioners and chronic pain patients, thereby improving the management and treatment of people suffering from chronic pain.

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The purpose of this project is to feature patients' perspectives on chronic pain and pain management as part of a larger effort to improve the delivery of care to patients with chronic pain in Kansas City and across the country. Having taken an interest in the topic of pain and pain management, I arranged a meeting with Myra Christopher, the Kathleen M. Foley Chair for Pain and Palliative Care at the Center for Practical Bioethics. Based at the Center, Ms. Christopher leads the Pain Action Alliance to Implement a National Strategy (PAINS) and, through her work, is building a national movement to change the way pain is perceived, judged and treated. My enthusiasm and admiration for Ms. Christopher's work led me to inquire about areas of research that would contribute to the mission of PAINS. This led to discussions with Dr. Joseph LeMaster and Dr. Kim Kimminau of the Department of Family Medicine at the University of Kansas, School of Medicine, who also have interest in chronic pain research, and I began developing a Clendening Summer Fellowship proposal under their guidance.

My goals for the Clendening Summer Fellowship are three-fold. For starters, I aim to gain insight into the lives of patients living with chronic pain. Developing a deeper appreciation for the challenges they face will no doubt prepare me to deliver compassionate, informed, and sensitive care to patients with chronic pain in the future. Given the prevalence of chronic pain in the United States, gaining this insight will be invaluable. Second, through working with the PAINS project and the Center for Practical Bioethics, I aim to gain practical experience in patient advocacy at a local and national level. I have accounted for time spent at the Center and for working with local organizers of the PAINS project in the timeline outlined below. Finally, I hope to conduct research that will make a meaningful contribution to the efforts of PAINS. By giving voice to patients with chronic pain and characterizing their experience with pain and pain management, this research may help to shape future PAINS endeavors in Kansas City and improve the lives of people living with chronic pain.

Description:

Relieving Pain in Kansas City, a community-based initiative involving PAINS, is a monthly meeting of patients living with chronic pain in the Kansas City area. Over the next several months I plan to attend these meetings in order to become involved with this local initiative of PAINS and become acquainted with the population of patients suffering from chronic pain in Kansas City. The patients suffer from a variety of illnesses, and each has a unique story to tell.

At the conclusion of the school year, I will begin learning the skills and techniques required for qualitative interviews and analysis with Dr. Kimminau, director of community health research and associate professor in the Department of Family Medicine at the University of Kansas Medical Center. I will also begin to review the relevant literature on pain and pain management. After this time, I will work

with Dr. Kimminau to select interview subjects from the *Relieving Pain in Kansas City* group and begin interviewing patients. The aim of these interviews is to gain an understanding of chronic pain patients' perspectives on pain and pain management. A set of sample questions may be found in Appendix B.

In addition to interviewing patients, I will work with local PAINS organizers at the Center for Practical Bioethics in order to gain practical experience in patient advocacy. The mission of PAINS is to advocate for and act collectively to actualize the recommendations set forth in the Institute of Medicine report, *Relieving Pain in America*. Carrying out this mission involves working on behalf of patients at a local and national level. Under the guidance of local organizers of PAINS, and in particular Myra Christopher of the Center for Practical Bioethics, I aim to become involved in various aspects of patient advocacy. Learning these skills will no doubt improve my skill and capacity for patient advocacy for future patients.

After a thorough review of the relevant literature and after completing patient interviews, I will compile and analyze the data using qualitative methods. The findings of the qualitative study will be included in a report for the Clendening Summer Fellowship. Additionally, the findings will be provided to local organizers of the PAINS project, an initiative of the Center for Practical Bioethics, to help them in their efforts to foster better understanding between practitioners and chronic pain patients, thereby improving the management and treatment of people suffering from chronic pain.

Timeline:

February – May: Attend monthly meetings of *Relieving Pain in Kansas City* in order to become acquainted with the local organizers of the PAINS initiative and the local network of patients with chronic pain.

May 17, 2014: End of Academic Year.

May 18 – 31: Develop skills and techniques required for qualitative interviews with Dr. Kim Kimminau and her staff. Review relevant literature on pain, pain management, and qualitative research methods.

June: Conduct interviews. Work with local PAINS project organizers at the Center for Practical Bioethics. Continue to review relevant literature on pain and qualitative research methods.

July: Analyze data. Continue to work with PAINS project organizers. Continue to review relevant literature. Write Clendening Summer Fellowship report.

August: Submit reports.

Methods:

Pending IRB approval, data will be collected through interviews with chronic pain patients associated with *Relieving Pain in Kansas City*, a local initiative of the PAINS project. All interviews will be conducted on a voluntary basis in private rooms at the University of Kansas Clinical Research Center at 4350 Shawnee Mission Parkway, Fairway, KS 66205; the CRC is the site of *Relieving Pain in Kansas City* meetings, so prospective interviewees will be familiar with the setting. Interviewees will be provided remuneration in the form of gift cards. Potential interviewees will be approached at meetings of *Relieving Pain in Kansas City*, given a description the project, and allowed to decide if they wish to

participate. Written consent will be obtained from each participant (see Appendix A). Audio recording will be employed in order to ensure accurate recording of the information obtained via interview.

The goal of the interview process is to obtain detailed, in-depth narratives and descriptions of patients' perspectives on living with chronic pain as well as the management of chronic pain. As such, lengthy interviews with fewer patients will be favored over short interviews with a large number of patients. Approximately 10-15 interviewees will be selected for interviews. Interviews with each patient will consist of at least one extended interview session and may include follow-up sessions as needed.

Under the guidance of Dr. Kim Kimminau, I have completed a preliminary review of qualitative methodologies, and on the basis of this review I plan to employ crystallization methods as articulated by Ellingson (2009) in the analysis of patient interviews. Qualitative interview methods and techniques will be practiced with Dr. Kimminau and her staff prior to interviewing patients. Additionally, medical literature pertaining to chronic pain and pain management will be reviewed and, when pertinent, included in the report.

For the duration of the project I will maintain residence in Kansas City. This expense, along with the cost of travel to and from interviews, monthly meetings of *Relieving Pain in Kansas City*, and work with PAINS organizers at the Center for Practical Bioethics in Kansas City has been detailed in the proposed budget below.

Contacts:

Myra Christopher
Kathleen M. Foley Chair for Pain and Palliative Care
Center for Practical Bioethics
Steering Committee Chair: The Pain Action Alliance to Implement a National Strategy (PAINS)

Dr. Kim Kimminau, PhD
Associate Professor
Director, Center for Community Health Improvement
University of Kansas, School of Medicine

Dr. Joseph LeMaster, MD, MPH
Associate Professor
Department of Family Medicine
University of Kansas, School of Medicine

Budget:

Housing:	\$600.00/month x 3 months.....	\$1800.00
Utilities:	\$60.00/month x 3 months.....	\$180.00

Budget (cont.):

Food:	\$150.00/month x 3 months.....	\$450.00
Transportation (gas):	\$75.00/month	\$225.00
Subject Remuneration:	\$20.00/person x 10-15 persons.....	\$200.00 - \$250.00
Audio Recorder:	\$50.00.....	\$50.00
Total.....		\$2905.00-2955.00

\$2500 of the proposed budget will be financed via funds provided by the Clendening Summer Fellowship. Additional costs, beyond \$2500, will be financed personally.

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Appendix A: Consent Form

I am a medical student at the University of Kansas, School of Medicine, and I am conducting interviews as part of a Clendening Summer Fellowship research project. The goal of the project is to study the perspectives of people living with chronic pain, especially their perspectives on healthcare.

If you choose to participate in this study, you will be asked some questions about the care you currently receive for chronic pain or the care you have received in the past. You will also be asked about your disease(s) and other factors that contribute to the nature of your experience with healthcare as it relates to your pain. Please take as much time as you need to answer the questions, and feel free to expand on any idea or related ideas that may occur to you. If at any point during the interview you are asked a question that you do not wish to answer, please express this and we will stop the interview or proceed to another question. All information will be kept confidential, and you will not be asked to give identifying information (e.g. name, address, telephone number) of any sort.

Participant's Agreement:

I am aware that my participation in this interview is voluntary. I understand the purpose and intent of the research. If, for any reason, I wish to stop the interview at any time, I may do so without having to give an explanation. I am aware that information obtained from this interview will be used in a Clendening Summer Fellowship research project and may be used in a presentation at the University of Kansas, School of Medicine. I have the right to review, comment on, and/or withdraw information prior to the project's submission. The information gathered in this interview is confidential with respect to my personal identity unless I specify otherwise. I understand that the audio from this interview is being recorded.

If I have any questions about this study I am free to contact the student researcher (Joel Burnett, jburnett2@kumc.edu, 816-547-9446). I have been offered a copy of this consent form, which I may keep for my own reference. I have read the above form and, with the understanding that I can withdraw at any time and for whatever reason, I consent to participate in today's interview.

Participant's Signature

Date

Interviewer's Signature

Adapted from <http://inside.bard.edu/irb/consent/>

Appendix B: Interview Questions

Note that the set of questions here constitutes a draft that is subject to revision following additional research into medical literature concerning chronic pain and pain management as well as additional training in qualitative interview methods.

1. How long have you lived with chronic pain? What do you understand the source of this pain to be?
2. Describe your typical day. How is it impacted when your pain is mild? Moderate? Severe?
3. What are you doing to manage your pain (e.g. medications, complementary therapies, etc.)?
4. How did you arrive at the approaches to pain management that you employ?
5. Is your pain management adequate? How could it be improved?
6. Has your attitude toward pain changed as a result of your experience with chronic pain? How?
7. What, in your view, are the barriers to improving your pain management? How might those barriers be overcome?
8. Specifically, what do healthcare providers do to help you in your chronic pain care? What do they do to hinder you?
9. How has chronic pain impacted your family life? Your social life? Your work life?
10. Does the experience of living with chronic pain carry personal meaning or significance for you? Have you discussed this significance with your family? Your healthcare providers?



Image from: www.oldhippie.org "a day in the life of a therapy dog"

MAN'S BEST FRIEND: AN EXPLORATION OF PET THERAPY

Clendening Summer Fellowship Proposal 2014

"Perhaps one central reason for loving dogs is that they take us away from this obsession with ourselves. When our thoughts start to go in circles, and we seem unable to break away, wondering what horrible event the future holds for us, the dog opens a window into the delight of the moment."

—Jeffrey Moussaieff Masson

Erin Eifler

University of Kansas School of Medicine
Class of 2017

Introduction:

I plan to spend my time as a Clendening Summer Fellow exploring an area of medicine that is often overlooked, but potentially very valuable: the use of therapy dogs in health care settings. A three-part project will help me comprehensively understand how therapy dogs function in our healthcare system and what their role may be in improving health status and quality of life for patients. The first part will consist of going into a variety of settings that use therapy dogs to shadow, observe and interview individuals who participate in relationships with the therapy dogs (patients, doctors, nurses, physical therapists, and dog handlers). Second, I will go through therapy dog training myself to more fully integrate the philosophy into my future medical practice and to appreciate the preparation required to effectively provide pet-based palliative care; I plan to continue volunteering in therapy dog venues throughout the duration of my career in medicine. Third, I will conduct a review of current literature regarding therapy dog use in health care settings to consolidate the evidence and delineate the gaps in our knowledge on the pros and cons of their use, with a particular emphasis on their effect on patient quality of life and health outcomes.

Background:

I became interested in non-traditional approaches to combating illnesses when I volunteered at Give Kids the World Village (GKTW) in Kissimmee, FL as an undergraduate. GKTW presents a sanctuary for families traveling to the Orlando theme parks on their children's wish trips. Every family staying at GKTW has a child with a life-threatening illness, which in many cases is terminal. The healing power of laughter, hope, and normality is demonstrated there every day. I saw children make turnarounds over the course of a week that our medical community would call impossible. Far from being "paranormal" or mystical, the uncanny recovery that sometimes occurred can be explained by my background in psychology: the mental status and outlook (positive or negative) of an individual absolutely has an ability to impact physical health.

Many of the families I worked with in the village told me that the crucial turning point came about by their children getting to "just be kids" for a while. They were able to forget that they were sick, eat ice cream for breakfast, and meet their favorite Disney characters for lunch. Obtaining a sense of ordinary and fitting in with a community appeared to go a long way towards changing the mental outlook of the families who stayed in the village with us. In my own experience, contact with dogs can produce a very similar phenomenon. No matter how stressful medical school is, I go home at the end of the day and can play outside with my dog. She sits with me while I podcast lectures, providing companionship, understanding, and gentle reminders that I have to get off of my chair and leave the house periodically throughout the day. My situation is certainly not as severe as that of our patients, but as the severity of a person's condition increases, the therapeutic effects of canine interaction may become all the more potent; I would like to determine if the relationship has empirical support.

For many patients, a vacation simply is not feasible – especially in the midst of a serious illness, but most could develop a relationship with a therapy dog. Contact with dogs is known to lower mental distress in those who feel socially isolated (Aydin, Krueger and Fischer, 2012). Everyone, from pediatric patients to those undergoing physical rehabilitation to geriatric patients living in nursing homes, has some potential to benefit from a canine companion coming to visit. Additionally, physical contact with dogs has been demonstrated to lower blood pressure and heart rate in individuals across a variety of settings and age groups (Vormbrock and Grossberg, 1988).

Physicians have a duty to not only eradicate disease, but also to promote health. “Health” certainly encompasses physical well-being, but mental and emotional states are equally important. To truly serve our patients, we must be able to address all three aspects of health. We have been taught time and time again here at KU Med that patient care is a team effort, and dogs offer something that no other member of our team possibly can. My goals for the proposed project are to understand first the exact contribution therapy dogs can provide, and second how I can best serve my patients by incorporating therapy dogs into my future practice. Based on my findings, I would also like to see pet therapy become a more integrated part of our treatment plans by spreading awareness to my colleagues.

“Dogs are our link to paradise. They don’t know evil or jealousy or discontent. To sit with a dog on a hillside on a glorious afternoon is to be back in Eden, where doing nothing was not boring—it was peace.”

— Milan Kundera

Description:

The proposed project is an immersion in the world of pet therapy taken from several different angles with the goal of providing a holistic understanding of its place within the larger sphere of our healthcare system.

PART I: SHADOWING

Shadowing will take place in the Kansas City and Lawrence areas. The volunteers that I will be shadowing with visit pediatric wards in hospitals, retirement homes, psychiatric wards, private practices, the cancer center, and rehabilitation facilities. Specific dates will be set as the summer draws closer, but all parties described in the methods section have already agreed to allow me to shadow and interview with them. Some of the locations I list are visited only occasionally, so the locations I may visit as a Clendening Fellow may vary slightly from this list. However, some areas are visited regularly and are more certain to be included in my project (see Appendix B).

I plan to do 3-5 sessions of shadowing each, with Amy Bennet, Dr. Steve Hendler, and Raven Rajani to gain as much experience as possible (please see Methods Section for contact information). Shadowing with Dr. Hendler will take place at his Leawood clinic. Both Amy and Raven frequent multiple settings where I can shadow and interview, including several areas of the KU Med hospital, nursing homes, education facilities and hospital settings in Lawrence; they have contacts who volunteer in other settings where I can also shadow if the settings we visit together do not give me a broad enough scope.

The beginning of the summer will be dedicated to shadowing with these volunteers and going through the therapy dog volunteer training myself with my dog. During visits, I will observe interactions between the dogs and patients, as well as interview patients, health professionals, and the volunteers themselves regarding their experiences with therapy dog programs (see Appendix A for interview questions). I plan to interview at least 1 healthcare provider and 3-5 patients during each visit, but may be able to obtain more interviews in some settings depending on the structure and length of each visit. Interviews with the volunteers may be conducted before or after a visit so that the volunteer may remain engaged in what he/she is doing throughout the session.

PART 2: THERAPY DOG TRAINING

Therapy dog training will be conducted through *Loving Paws* in Lawrence, Kansas. Training is a six-week process that will begin late in the spring semester (May, exact start date TBA) and continue into early summer (June). I am already registered for the class and been given the introductory materials; I will be contacted as soon as dates have been set. In addition to classroom hours, there is a fair bit of outside work required by the curriculum, so the training along with the shadowing will occupy me completely through the beginning of the summer. There will be a certification process at the end of training that will allow me to volunteer on my own with my dog, Fia. At the end of the summer (August 9), there will be an additional certification process through *Pet Partners* that will allow me to volunteer at KU Med beginning in Fall 2014.

PART 3: LITERATURE REVIEW

The literature review will be conducted throughout the duration of the project, but will increase in intensity after the training has finished and my schedule is more open. Specifically, I plan to use library resources such as PubMed, Access Medicine, and PsycInfo to gather data on the psychological and physiological outcomes associated with pet therapy. The goal of my analysis is to delineate the role pet therapy currently plays in the healthcare system, where further research is needed, and how pet therapy should be integrated in the future. From my undergraduate studies in psychology, I have extensive experience in reviewing journal articles and integrating them into a meta-analysis style research paper. Accordingly, my research and interview data will be compiled into a paper, with the goal of eventual publication.

Projected Timeline:

Mid-May – Mid-June	Pet Therapy training with <i>Loving Paws</i>
Mid-June	Pet Therapy Certification test with <i>Loving Paws</i>
June	Shadowing (~15 days) and interviews (3-5 per shadowing event)
June-July	Literature review and compilation of interview responses
August 9	Certification seminar and test with <i>Pet Partners</i>

Methods:

Shadowing, training, and research will be conducted as outlined above. I have contacted several individuals who have agreed to assist me with this project:

- I. Amy Bennett, of *Pet Partners*, is in charge of the pet therapy program here at the University of Kansas Hospital. She has been involved with therapy dog work for many years. I have spoken with her extensively about her experiences and the training process. I will be shadowing her and her dog, Ginger in the pediatric and psychiatric wards, as well as in nursing homes that she frequents. She is also the person in charge of the certification process, which I have already discussed with her, I will undergo in August with Fia that will allow me to volunteer at KU Med beginning Fall 2014.

2. Dr. Steve Hendler is a physician in physical medicine and rehabilitation. He works in Leawood and brings his trained therapy dog, Sesame, to work with him several mornings each week. I will be shadowing with Dr. Hendler as part of my project.
3. Raven Rajani is a therapy dog handler and the founder of *Loving Paws* Pet Therapy program in Lawrence. Fia and I will be completing our therapy dog training with her, and also will be shadowing with her as she works with her dogs. Raven volunteers in a variety of settings, including hospitals in the Lawrence and Kansas City area, the cancer center, and even our library here at KU Med during exams.
4. Dr. Jessica Kalender-Rich is a physician here at KU Med in the Landon Center on Aging who has agreed to be a faculty mentor for this project. She works in geriatrics and palliative care and has experience in settings where therapy dogs are present. Dr. Kalender-Rich conducts her own research and has also previously served as a mentor for student research.
5. Cathy Engmann is the contact at the KU Med hospital with whom I have spoken briefly; she will be working with me closely to get my paperwork in order to become eligible to shadow inside of the hospital.
6. Heather Entrekin and her husband raise puppies that will become therapy dogs in homes. She has put me into contact with many of the other individuals I have spoken with and has agreed to be a resource for me during my investigations.
7. Carrie Criss is in charge of the *Pet Pals*, a long-standing and successful program at Children's Mercy Hospital. While I cannot go into CMH for shadowing or volunteering, Carrie has graciously agreed to speak with me and contribute her perspective on their program and its effects on the patients.

For the duration of my project, I primarily be living at my home in Kansas City. My parents live in Lawrence, so I will be able to stay with them during periods of training or shadowing there. Upon acceptance as a Clendening Fellow, I will contact the IRB to determine if my project requires approval for conducting the interviews. I have previous experience with getting IRB approval, so do not anticipate any difficulties with obtaining approval or exemption. An expected budget is outlined below, and any additional expenses will be covered by applying for summer financial aid.

Expected Budget:

Description	Expected Cost
Rent for June and July	\$1200
Utilities	\$300
Food and Living Expenses	\$400
Gas and Travel Expenses	\$200
Cost of Training and Certification	\$200
Total	\$2300

"Dogs are minor angels, and I don't mean that facetiously. They love unconditionally, forgive immediately, are the truest of friends, willing to do anything that makes us happy, etcetera. If we attributed some of those qualities to a person we would say they are special. If they had ALL of them, we would call them angelic. But because it's "only" a dog, we dismiss them as sweet or funny but little more. However when you think about it, what are the things that we most like in another human being? Many times those qualities are seen in our dogs every single day-- we're just so used to them that we pay no attention."

— Jonathan Carroll

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Vormbrock J, Grossberg J. Cardiovascular effects of human-pet dog interactions. *Journal Of Behavioral Medicine* [serial online]. October 1988; 11(5):509-517. Available from: PsycINFO, Ipswich, MA. Accessed February 6, 2014.

Appendix A: Interview Questions

Interviews will be brief, to minimize interference with the visits. My goal is to assess what the experience is like from the viewpoints of the different people involved, and eventually to compare those viewpoints to previous research regarding these relationships. I will also take observational notes during my visits.

1. Volunteers
 - a. How long have you been volunteering with pet therapy?
 - b. What experiences brought you to this area of work?
 - c. What changes do you see in patients and staff while you are volunteering?
 - d. Why is therapy dog work important to you?
 - e. What kinds of settings do you see the most benefit from your work? The least?
2. Health Providers
 - a. How has pet therapy been a part of your practice?
 - b. What benefits do you see for your patients from visits with therapy dogs?
 - c. Do you find pet therapy to be a useful part of healthcare? Why or why not?
 - d. Are there negative experiences that you have had with these programs?
3. Patients
 - a. How many visits have you had with therapy dogs?
 - b. Do you have pets at home?
 - c. Have you spent very much time in this healthcare facility?
 - d. Have you spent very much time in healthcare facilities that do not have pet therapy programs?
 - i. If so, what are some of the differences in how you felt at the various facilities?
 - e. Do you feel that you benefit from visits with therapy dogs? How?
 - f. In your experience, are there negative aspects of pet therapy visits?
 - g. Do you find pet therapy to be a useful part of your healthcare?

Appendix B: Shadowing and Training Locations

While other locations may be added, I have discussed shadowing at these locations with my contacts.

SHADOWING LOCATIONS

1. University of Kansas Hospital
3901 Rainbow Blvd.
Kansas City, KS 66160
2. Disability Management Associates (Dr. Steve Hendler)
11111 Nall Ave.
Leawood, KS 66211
3. Anschutz Library
3101 Hoch Auditoria Dr.
Lawrence, KS 66044
4. Lawrence Cancer Center
330 Arkansas St., Suite 120
Lawrence, KS 66044
5. Lawrence Presbyterian Manor
1429 Kasold Dr.
Lawrence, KS 66049

TRAINING LOCATIONS

1. Loving Paws Animal Therapy
3 E. 7th St.
Lawrence, KS 66044
2. Pet Partners has a P.O. box in Overland Park, and my training session will be at UMKC (5100 Rockhill Rd., Kansas City, MO 64100)

Raven also occasionally visits places like the Douglas County Jail and Willow Domestic Violence Center. I would like to be able to visit these additional locations if she is able to schedule any dates during the tenure as a Clendening Fellow.

Listen:

Investigating the educational potential of end-of-life experiences

Clendening Summer Fellowship Proposal

Keenan Hogan

University of Kansas School of Medicine

February 17th, 2014

INTRODUCTION

Separation of self and non-self is more than a biological concept and not only surfaces with an immune response, but also in our reaction to hearing the experiences of others. The practice of empathy is in large part an attempt to shrink the emotional distance we create, to help us understand and share in the experiences of others. For physicians this task is complicated by the demands of professional objectivity, but it nevertheless remains a central tenet to communication in the patient-physician relationship, particularly in the context of end-of-life care. Unfortunately, there is little to no consensus on how medical students should be trained¹ in the indispensable, but ill-defined, set of skills needed to actively listen, appreciate and communicate with patients living and dying with terminal illnesses. The combination of inconsistent curricula with such an exceedingly complex and multi-faceted educational burden warrants investigation into possible improvements for end-of-life care.

This project seeks to specifically explore the role of patient experiences in educating medical students and humanizing the process of end-of-life care. The research will follow three primary investigations. First, University of Kansas School of Medicine (KUSOM) students will be surveyed regarding their ideas on the educational goals of the project and how they should be measured, the applicability and relevance to their education, and attitude toward their personal preparedness and a physician's responsibilities in caring for patients in end-of-life care. Second, physician-referred and consenting patients will be video-recorded while relating their experiences by asking and answering questions of other patient participants, which will be incorporated into a final edited product. Third, KUSOM students will be surveyed regarding their response to the patient narratives and the format, including qualitatively-derived measures identified during the original survey.

BACKGROUND

In 1997, Dr. Christine Cassel chaired a committee of the National Academy of Sciences' Institute of Medicine investigating how to improve end-of-life care², making inquiries that would progress the practice of palliative care in the years to follow. Positive strides have been made in terms of recognizing palliative care as a specialty, improving pain management and health professional training, but the overall education of medical students regarding end-of-life care remains inadequate³.

In light of an impending demographic shift, which will greatly enhance the need for healthcare providers trained to care for chronically and terminally ill patients⁴, several curricular models have been advanced. To fulfill Liaison Committee on Medical Education requirements, most schools have integrated didactic lessons into the pre-clinical curriculum³; some schools, including KUSOM⁵, have experimented with short third-year hospice clinical rotations; Harvard runs a four month long program for only 20-30% of their first-year class, but includes extensive patient contact⁶. While each approach presents certain strengths and weaknesses, they all represent an attempt to provide medical students with early and meaningful exposure in order enhance future care. However, multiple constraints, such as a relative paucity of research and time available in an already-packed medical school curriculum, have added to the complexity of discovering the best educational paradigm.

Since the majority of my medical school colleagues will inevitably interact with patients living and dying with a terminal illness, I am personally interested in investigating a possible format for sharing patient experiences in a feasible, constructive and substantial way, as well as students' perspectives on this aspect of their education. This includes considering the role of formal (didactic), informal (observing/practicing) and hidden (behaviors/constructs) education. It has been established that the hidden curriculum of physician attitude and behavior can have a negative impact on students regarding empathy and compassion in end-of-life care^{7,8}, but this project may help to provide an educational opportunity in combining positive elements of formal and informal curricula to preempt these pitfalls.

Currently, medical school graduates across the country feel unprepared to care for dying patients, which corresponds with stress and burnout⁹. By experiencing terminal patients and the topic of death (often taboo in the hidden curriculum) in a supportive and educational environment early in medical school, students will have the opportunity to learn to develop coping skills and comfort with end-of-life care. For example, the video product in the format of a small group learning session could feasibly be integrated into the curriculum and provide students with an early exposure to the questions and concerns of real patients in a safe environment.

This research is not a solution, but an attempt to answer several questions about the educational process and a possible tool to aid in improving end-of-life care. In the end we need humanistic physicians, and lectures and protocol alone cannot adequately relate human experience. I learned this lesson working for two years in high school as a Certified Nurse Aide at a nursing home, and I have witnessed the overwhelmingly positive impact made by clinical correlation patients in class. I believe this project will be challenging, but I also believe it is worth it.

DESCRIPTION

The first step of the project primarily includes the creation and aggregation of several documents for the KUMC Human Subjects Committee (HSC):

- Initial student surveys will be developed based on a review of the literature and previously described research questions, combining demographic, Likert scale and open-ended questions.
- Post-surveys will be similarly developed, but will be filled out after student participants have viewed the project video product. Since a portion of this survey will be developed based on the results of the initial survey, it may be delayed in being submitted for HSC approval.
- Consent and release forms for patient participants will also be submitted, along with proposed pre-interview instructions and a post-interview survey based on research citing interviews with terminally ill patients who reported little to no stress (89.7%) and some benefit (46.5%) as a result¹⁰.

After being submitted electronically for voluntary participation by first, second and third-year medical students, the data will be systematically recorded. The results will be subjected to both standard correlation measurements and qualitative thematic analysis, which will influence the content of the post-surveys prior to submission for approval.

Prior to interacting with patient participants I will prepare with a combination of shadowing experiences. In coordination with palliative care physicians at the Westwood Clinic and the consult team in the hospital, I will shadow to gain an appreciation for the specialty and patient interaction. This will be supplemented by Kansas City Hospice House weekly lectures and literature referred by Dr. Bartlett and her colleagues.

Patient participants will be selected and invited by their physician, who will provide a referral if they are interested, which has been shown to be an effective approach in a similar project utilizing video-evaluation of a small patient population¹¹. After establishing a time for the interview, the patient will be supplied with the relevant forms and information, and the interview will be followed by a short survey. Given that these interviews will be based on physician referrals, they will most likely be scheduled irregularly throughout the duration of the summer. Subsequently, the video product will be a continual work-in-progress and will be revised as additional interview material becomes available.

The format of the interview has been designed in an attempt to remove the documenter from the patient experience as much as possible. With this goal in mind, the first patient participant will lay the foundation for the subsequent interview by supplying questions for the next patient participant, and so on. However, a set of basic instructions will be provided to guide the participants through this format, and individual patient narratives outside the scope of patient-proposed questions will be included.

Several times will be reserved, along with food as incentive, for students to view the video product and fill out surveys. The results of the post-surveys, initial surveys and patient surveys will be included in a comprehensive written assessment of the research results.

TIMELINE:

March – April	Develop surveys, instructions and consent forms to submit for HSC approval
April – May	Hospital and clinic shadowing, KC Hospice House lectures weekly
May	Send initial surveys, receive and analyze results
June	Develop post-surveys to submit for HSC approval
May – July	Schedule and complete interviews, edit video
August	Post-survey groups
August	Compile, analyze and write up results

**I understand that if my project timeline runs into the fall semester I will continue to work on the research project to completion.*

METHODS

Development of this project has been greatly facilitated by Dr. Christi Bartlett, KU Palliative Medicine Fellow (letter added as APPENDIX A). She has coordinated for physicians at the Westwood Clinic to refer patients for the project as well as approval to use the clinic as a location to conduct the interviews, if

necessary. The project has also been coordinated with Dr. Karin Porter-Williamson, Medical Director for Palliative Care Services.

Shadowing experiences were similarly coordinated. Weekly lectures at the KC Hospice House are open to medical student attendance.

Video recording equipment owned by KUSOM will be used, which has been approved for use by Ann Alexander, Medical Education Technology, and Dr. Giulia Bonaminio, Associate Dean for Medical Education (letter added as APPENDIX B).

Video editing will be performed primarily using Adobe Premiere Pro and Soundbooth as part of the Creative Cloud download package available through KU. I have significant prior experience using this software and am confident in using it for this project. DVDs will be made and provided to the patient participants if they would like a copy, in addition to a copy for use in the post-surveys.

CONTACTS:

Dr. Christi Bartlett
Palliative Care Fellow

Dr. Giulia Bonaminio
Associate Dean – Office of Medical Education

Dr. Karin Porter-Williamson
Medical Director – Palliative Care services

Ann Alexander, Program Manager
Medical Education Technology

BUDGET

Video editing software (Adobe Creative Cloud download rental for \$20 per month for 4 months through KU)	\$80
USB DVD disk writer and blank DVDs	\$70
Travel (additional 70 mile commute to/from Eudora approximately twice a week for 12 weeks at 30 miles per gallon estimating \$3 per gallon)	\$168
Food for survey groups (estimating 5 pizzas for 4 groups of 20 students)	\$200
Rent and utilities (June – July)	\$1200
TOTAL	\$1718*

**I understand that if my costs exceed the budget I will be responsible for the difference.*

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**Assessing the Burden of Malaria at the Pothawira Clinic in
Malawi**

A Clendening Summer Fellowship Proposal

Devin Kennedy

2014

I. INTRODUCTION

An estimated 627,000 people died from Malaria in 2012 with the largest number of deaths among young children in sub-Saharan Africa. Malawi is a small agricultural country in Africa and although progress is being made in reducing the prevalence of malaria, it is still one of the leading causes of morbidity and mortality. Pothawira clinic serves the Salima area of Malawi with around 125-150 children and mothers treated at the clinic each week for malaria related symptoms. The purpose of this study is to determine the burden of malaria among patients treated at the Pothawira clinic. This will include collecting data on the current number of patients presenting with malaria-related symptoms, utilization and demand rapid malaria tests and medicine for treatment, and awareness of prevention techniques among the populations that come to the clinic. This project will include going through the limited records that are available at the clinic and collecting survey and observational data over an 8-week period regarding the chief complaints of those entering the clinic. This data will serve as a base line to gain an understanding of the demand that malaria and malaria related symptoms puts on the clinic, its resources, and the people in the surrounding villages.

II. BACKGROUND

This project includes many aspects of health and medicine that are important to the globalized world, to the University of Kansas Medical Center (KUMC), and to my area of personal interest as well. Malawi is one of the more underdeveloped countries in the world and although the Malawian government and people have come along way in overcoming corruption and economic hardship; widespread poverty and disease still plague the population. The country relies heavily on outside aid in all sectors of its infrastructure, but particularly in health. There are a number of overseas organizations and international programs that are partnering with local groups and clinics to better the lives of the Malawian people. This type of international collaboration and focus on global health is a key movement in the healthcare systems of today and a focus seen throughout KUMC.

My personal interest and journey in international healthcare began long before the start of this proposal. I have served in many underserved areas throughout my life, and each experience has only deepened my goal to focus on global health in my personal career. My path to medicine started by working with special needs children in several different environments: summer camps, school, a Mexican orphanage, and mission trips. I was fascinated by the difference in capabilities of children with different access to medical and emotional care. During my undergraduate career at the University of Arkansas I spent two years studying the cultural effects of HIV/AIDS in South America. I eventually wrote and defended an honors thesis, "Theory and Reality in Public Policy: The Case of HIV/AIDS in Contemporary Chile" based on this research. The project took me on a study abroad to Chile where I was able to use my Spanish language skills, immerse myself in the society, and gain a better understanding of the cultural and socio-economic barriers that face many Chileans in their access to treatment for HIV/AIDS. After my study abroad experience in Chile, I realized that I am not just interested in the direct medical needs of people but also in their access to care and their barriers to that care.

All of my past experiences and international travel have brought me to where I am today - in medical school. I have become involved in a variety of organizations and activities in medical school in order to continue working with global health and international programs. I have been particularly interested in OBGYN as a specialty for the future because of the access for women and children and their particularly unique medical and cultural obstacles in the world today. I serve as a Junior Student Director in the Women's Health Night at the Jaydoc student clinic and I am a member of the Student Governing Council of KUMC. Through these activities, and after showing interest in a Clendening Fellowship, it was suggested by faculty members that I reach out to Dr. Sarah Kessler.

Dr. Sarah Kessler, from the department of Family Medicine in their Research Division at KUMC, has researched global health and medicine in a variety of ways. Most of her research focuses on decreasing the impact of HIV/AIDS in Africa, particularly through reducing the number of infants born with the disease. Dr. Kessler has worked tirelessly on the HIV Infant Tracking System (HITSsystem) that aims to advance the communication between patients and healthcare providers in order to improve care. Dr. Kessler's research with the HITSsystem has now expanded from Kenya and Uganda to Malawi as well. Dr. Kessler explained to me the type of work that she does and the populations of people that she works with, and was especially excited about the possibility of the Pothawira clinic in Malawi being a future option for an international rotation for KU Residents. We spoke about my past experience, and the current needs of her work and those with whom she works. While data collection is taking place for HIV and AIDS patients, there is very little information on the demand that malaria puts on the clinic in Malawi. Although it is known that malaria symptoms are a large portion of chief complaints at the clinic, especially for pregnant women and children, there is no baseline data to use for ordering treatment and medication, obtaining rapid tests, tracking statistics, or for targeting community based outreach and education for prevention.

III. DESCRIPTION

Malaria

Malaria is the most important of the parasitic diseases in humans, transmitted by the bite of an infected mosquito. There are five species of *Plasmodium* parasites that cause Malaria and *P. falciparum* is the species that causes almost all deaths due to malaria. *P. falciparum* is the most common species of malaria in the Salima District of Malawi. The disease can be difficult to diagnose, as some of the first clinical symptoms are very nondescript. These early symptoms can include fever, chest pain, abdominal pain, and headache. These are all signs of most viral infections as well. Untreated malaria due to *P. falciparum* can lead to severe anemia, hypoglycemia, renal failure, and convulsions. Underdeveloped or suppressed immune systems put patients at a particularly high risk for complications with malaria. This includes pregnant women, young children, and patients with HIV. Over 90% of the world's malaria cases and deaths are found in sub-Saharan Africa where poverty and widespread HIV infection put many people at increased risk for

infection and complications. The tropical climate of the region, and the extended rainy season increase the transmission of the parasite.

Because of the nature of the early symptoms of malaria infection, Rapid Diagnostic Testing (RDT) has been developed. The RDTs are a simple, quick antibody card or stick test to determine malaria status in patients, and are recommended for use with anyone presenting to a clinic or hospital with fever in the sub-Saharan region of Africa. Uncomplicated malaria can be treated with oral Chloroquine, but severe malaria is a medical emergency that will require much more than oral medication. It requires nutrients, fluids, steroids, malaria medication, sometimes hemodialysis and intensive nursing and monitoring. For pregnant women, quinine or quinidine should be used as prenatal antimalarial treatment. There are also some prevention techniques, outside of prenatal care, that can be used as well. The most widespread and promoted prevention technique is the use of nets for sleeping underneath in the home.

Malawi is a land-locked country in south-central Africa where malaria is pandemic. The most common species of parasite in Malawi is *P. falciparum* and it causes almost 98% of all infections there as well as almost all deaths due to malaria. Transmission of the disease peaks during the rainy season from November to March and is also higher in the wetter areas close to the large Lake Malawi on the East side of the country. A study completed by the Presidents Malaria Initiative and Operational Plan estimates that around 6 million cases of malaria are treated each year in Malawi. This accounts for 40% of all hospitalizations of children under five and up to 60% of hospital deaths in this age group are also attributed to malaria and malaria related anemia. Malaria is essentially a completely preventable and treatable disease, and yet it kills hundreds of thousands of children and adults each year. There are a number of organizations and projects including the Malaria Operational Plan and Global Health Innovations that are working to decrease these numbers with RDT, treatment, prenatal care, as well as increased prevention education and action, but there is still more work to be done.

Pothawira Clinic

Pothawira means “safe haven” in Chichewa, Malawi’s native language. It was created and is still run by Malawians Peter and Emma Maseko. Pothawira is a complex that has a church, school, orphanage with children’s homes, and a medical clinic that serves the Maganga village and beyond. The clinic itself sees and treats nearly 150 malaria cases each week. Dr. Kessler works closely with Brad Gautney and Global Health Innovations to bring both the HITSystem and malaria care to Salima, Malawi and the Pothawira clinic.

Project Proposal

This project has been split into stages: Preparation, Observation and Assessment, and Consolidation and Analysis.

The **preparation stage** will be completed before I travel to Africa. It includes working with Peter Maseko and Dr. Kessler to determine how best to assess the burden of Malaria on the Pothawira clinic as well as developing the skills I will need to complete the project once I am on the ground. One of the most important parts of this stage is gaining an

understanding of the language in Malawi so that I can be effective in the clinical setting. Over the next few months I will be studying Chichewa through an online program called Instant Immersion. On top of this I have purchased a study dictionary and will be specifically building my medical vocabulary. Outside of intensive language studies, it is important that I continue to increase my knowledge of Malawian culture, Malaria, and the workings of the Pothawira clinic. Dr. Kessler has continued to offer advice and guidance on the project and I will be keeping in close contact with her as I further my plans before going to Africa. The main thing that I will be working with Dr. Kessler on is developing a survey that both contains the information that is needed to assess patients' knowledge, attitudes and behaviors regarding malaria prevention and treatment that is also feasible to give in the Pothawira clinic setting. The World Health Organization has developed a survey that has been used as a rapid assessment of malaria across many regions of the world and this has been a great start to developing a survey to use in Malawi. Before leaving I will be meeting with Brad Gautney to learn more about how the clinic works on a day-to-day basis, and how I can be helpful with patients while I am there. I will also be corresponding with Peter Maseko and his daughter, Dr. Annie Maseko who resides in Houston, TX, so that I know more about the kind of data and assessment that will be helpful to him and his team in the future.

The **observation and assessment stage** will be performed in country. In her research, Dr. Kessler emphasizes the importance of understanding the culture of the people you are working with, before you can truly understand the problem. In agreement with this philosophy, my first few days in Malawi will be strictly observational. It is a time to see how everything works at the clinic and experience first hand the culture in Malawi and at Pothawira. After getting more comfortable with the surroundings, my first step in the assessment of the clinic is to look at past records and patient logs. The clinic does not keep extensive medical records for the average of 200 patient visits per day, but there is data available that is associated with the pharmacy. There will be time spent on deciphering the records with the ultimate goal of taking a random sample from each clinic day to gauge the load of malaria-related admits per month. After which, I will be doing more extensive data collection during the rest of the 8 weeks that I plan to be in Malawi. This will include continued sampling and observation of patients, but also distribution of a survey to assess patient education and use of prevention strategies. Collaborating with Drs. Maseko and Kessler, I will continue to discuss the best strategy for collecting survey data that is least invasive to patient flow. I will remain flexible to the method that works best after arriving at Pothawira and assessing the physical layout to maximize efficiency and privacy for survey participants.

The third stage is the **consolidation and analysis** time period. This will partially be completed in Malawi, and partially upon my return to the United States. The statistical and observational information collected at Pothawira will be entered and save electronically in excel which will facilitate basic analyses to graph and map frequencies and proportions of malaria-related outcomes. This format can be imported to more sophisticated statistical analysis software if more sophisticated analyses are required. This baseline data could be used to document utilization and need for materials such as quinine treatment and RDTs per month. It will also provide information on the outcomes of the efforts made by Global

Health Initiative and others at the Pothawira clinic to improve prevention and education for malaria in the surrounding villages. Experiences gained over the summer may even be used to help create future prevention and education outreach programs for the Salima area. KUMC is also in the process of building a relationship between the School of Medicine and Pothawira as a global health-training site, and my involvement at the clinic in Malawi can contribute to these efforts as well. After return to the US I will be gathering all of my information for my final Clendening report and plan to make any data collected or product completed available to KUMC.

Timeline

February

- Submit Clendening Proposal
- Begin Chichewa Instant Immersion Classes

March

- Solidify schedule
- Continue planning and preparation with Dr. Kessler
- Identify any vaccines or shots needed for travel to Malawi
- Make contact with Dr. Peter Maseko
- Purchase Airline Tickets
- Continue Chichewa classes

April

- Meet with Brad Gautney; learn medical practices at the clinic
- Continue gathering information on the clinic and malaria
- Solidify survey questions
- Continue Chichewa classes

May

- Continue Chichewa classes
- 22nd: Leave for Lilongwe, Malawi
- Week 1: Meet Maseko family, tour Pothawira, and get comfortable

June

- Help in Clinic and shadow patients and staff
- Find and study patient log
- Make necessary changes to survey and survey administration strategy
- Begin survey distribution and conversations

July

- Continue to help in clinic and shadow patients and staff
- Continued survey distribution, write-up of observations
- Interview Dr. Maseko about next steps to address clinic needs
- Explore surrounding villages
- 24th: Return to United States
- Collect and analyze data in aggregate form

August

- Continue analysis process with consultation from Dr. Kessler
- Prepare Write-up and presentation for Clendening Fellowship

IV. METHODS

The Pothawira clinic in Malawi is tied to research and staff at KUMC. My primary advisor/contact is Dr. Sarah Kessler who has traveled to the clinic multiple times. I plan to land in Lilongwe, Malawi on my date of arrival. From here Dr. Maseko will pick me up from the airport and provide transportation to Salima. While in Malawi I will be staying with Peter and Emma Maseko for about \$25 a night. At the Maseko household, room and board will be provided, and I will be traveling with Dr. Peter Maseko to and from the clinic each day. Extra transportation around Malawi may not be necessary but is available.

In terms of IRB, I will be submitting a request for a determination of Not Human Subjects Research. My collection and presentation of data will be in aggregate form and each patient will be de-identified with no names or personal information. The primary purpose of the data collection is to improve services at Pothawira clinic and is not intended for publication.

V. BUDGET

Item	Cost
Round-trip Airfare -Kansas City to Lilongwe, Malawi	\$2,400
Room and Board w/ Dr. Peter Maseko	\$1,500
Extra Necessities/Expenses	\$500
Total	\$4,400
Clendening Fellowship	\$2,500
Out-of-Pocket	\$1900

- In order to cover the out-of-pocket expenses my family has agreed to help in any way they can, but I am also prepared to take out a loan from my fall stipend to cover the extra expenses over the summer

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Introduction

Sex work is one of the oldest professions, existing since biblical times. There are several arguments against sex work including broken morality, disease related to promiscuity, the lack of protection of the family, and the devaluing of women (Sieberg 2001). Despite the concerns and laws against sex work, sex work remains an active profession for many women in the United States and other countries. Although sex work is illegal in most of the United States, it is not in other countries such as Costa Rica. Therefore, for my summer project, I want to investigate the impact of government regulation on sex work in Costa Rica from a sex worker's perspective; specifically, how government regulation impacts sex workers' daily life and quality of healthcare. Previous studies show that legally regulating sex work has many positive public health benefits such as monthly screening for sexually transmitted diseases and obligatory condom use. Without legal sanctions, it is more difficult to ensure the health and safety of sex workers and their customers (Loff, Gaze et al. 2000).

Background

I have traveled extensively abroad, working and studying in more than thirteen countries. Although I have visited many countries, I have only lived in two for a long period of time. I lived in San José, Costa Rica for almost two months, taking courses in Spanish and Latin American Studies. In my Latin American Studies class, I learned that sex work was legal in Costa Rica. In fact, due to universal healthcare in Costa Rica, sex workers can get regular physical exams. They carry health cards that state known diseases and last date of physical; this is important in price negotiation. I was immediately intrigued by this system especially since sex work is illegal in most of the United States and such an uncomfortable subject for many people. I did not realize the prevalence of sex work in the country until I traveled with friends to Jacó, Costa Rica to enjoy the nice beaches on the Pacific Coast. While at a bar one night, a gentlemen (most of the male tourists are from China, Venezuela, etc. and are well groomed in expensive suits) asked the bartender to ask me for "my price". I was very confused. What made him think that I was a sex worker? Then, after looking around the bar, all of the women, except for my friends and I, were either lined up waiting for offers or sitting at tables with their buyers. How could I have missed this scene upon first entering the bar? That is to say, sex work in Costa Rica is not very explicit upon first glance.

From my experience, I began wondering about price negotiation. What is the cost of sex in Costa Rica and what is it based on? Perhaps it is based on known diseases on the health card, age, attractiveness, condom usage, sex act, sexual partners, etc. Specifically, how do sex workers in Costa Rica feel on a daily basis and how does sex work impact their overall health? This project will contribute directly to my career goal of pursuing a career in family medicine with an international healthcare focus by giving me experiences in an international context working on an important public health issue. I also want to become fluent in Spanish, possibly working with Doctors Without Borders in Spanish-speaking countries. I have been to Costa Rica twice, and I know the city of San José well. This summer project will pave the way for my future endeavors.

Description

In the United States, 90,000 arrests are made yearly due to violation of sex work laws. A member of the Atlanta Task Force on sex work once stated that the cost was a ‘waste that burdened the courts and lowered police morale’ (Weitzer 1999). Furthermore, sex work laws only *contain* the issue of sex work by regular police raids in known sex work zones. Sex workers are fined, serve a small amount of jail time, and then are released and relocate to a different area to continue exchanging sex for money or drugs (Weitzer 1999). The act of containment of sex work is common in the United States especially when looking at the prevalence of sex work in Las Vegas, Nevada, where sex work is legal (and not so overt), compared to other cities where sex work is not legal.

Furthermore, the risk of unintended pregnancies and sexually transmitted diseases (STDs) also leads to additional costs associated with sex work. In 2006, all unintended pregnancies in the United States resulted in \$11 billion in cost. Annually, family planning services are estimated to prevent nearly 2 million unintended pregnancies and save \$4/person in Medicaid expenses. Similarly, the annual cost of STDs in the United States is approximately \$15.9 billion. Many cases of STDs are not reported and undiagnosed. There are approximately 19 million new cases of STDs each year, many occurring among those 15-24 years of age (healthypeople.gov). Legalizing prostitution could possibly curtail some of the expenses of unintended pregnancies and STDs in the United States.

Although law enforcement of sex work has proven to be ineffective, sex work is largely illegal in the United States. One argument for the persistence of regulations outlawing sex work is that sex workers are at a higher risk for violence, exploitation, drug use, and poor health outcomes. In a survey conducted in San Francisco that questioned 200 street sex workers about their experiences, researchers found that two-thirds were victims of assault and 70% were raped by customers (Weitzer 1999). These results were self-reported by women who had reached out to service agencies or were questioned while in jail or on the street. Previous studies have noted that there may be less violence against call girls (“upscale sex work”) as compared to street sex workers (Weitzer 1999). Other arguments against sex work include immorality, adverse community impact due to “overt street behavior,” and the negative impact on children who may see transactions or may be approached by sex workers or their customers. In sum, the argument against sex work is that it destroys community and promotes disorder (Weitzer 1999).

On the other hand, sex work is legal in Costa Rica for men and women 16 years of age and older and is government regulated (Downe 1997). Little research exists to determine if the same problems exist in Costa Rica as in the United States or are there different issues. What exactly is the impact of government regulations on sex work in Costa Rica? First and foremost, health is a prominent feature of Costa Rica’s national identity as evidenced by their universal healthcare policy. By public opinion, female sex workers are labeled as diseased (Downe 1997). However, a previous study showed that among 2,500 female sex workers tested for HIV/AIDS, there were no positive tests for the disease. In fact, the women were well aware of infectious diseases and transmission. Researchers interviewed female sex workers, and they associated violence with the risk of HIV/AIDS, illustrating the value of HIV/AIDS education. The National Health Commission in Costa Rica, after the first incidence of AIDS in 1980, launched a public health education campaign via advertisements, public schools, pamphlets, etc. (Downe 1997). It seems that the Costa Rican government invests many resources into educating its citizens on health issues, which may be one positive aspect of government regulated sex work.

Furthermore, education and empowerment have been proposed as potential harm reductions in sex work. For example, educating a female sex worker on personal safety and negotiating condom use with potential customers invokes empowerment and self-esteem

(Rekart 2005). Because Costa Rica has universal healthcare, it seems that female sex workers readily have access to health education and services, which possibly makes legalized sex work a relatively safer occupation compared to illegal sex work. It is important to make the distinction between sex work being decriminalized versus it being legalized. Decriminalization of sex work is unregulated; however, legalization of sex work is regulated with licensure and registration (Weitzer 1999).

I want to know the impact of legalized sex work in Costa Rica from a sex worker's perspective. I plan to conduct surveys with female sex workers at Hogar de la Esperanza, a home for many street workers in San José, Costa Rica. My questions will focus on partner selection, condom negotiation, health card use negotiation, type of sex acts, pregnancies, and self-reported STDs. Survey questions will be in a multiple choice format rather than open-ended (see supporting documents section for my questionnaire) to allow for direct quantification of responses. I have chosen to specifically focus on women to explore the theories on education and empowerment for female sex workers. I will have my questionnaire translated by Ruth Pedraza, President of Latino Medical Student Association, and pilot test it with a small sample (~5) women before administering to the full sample (~50). My objective for this project is to describe the public health implications, whether positive or negative, of government regulated sex work from a sex worker's perspective. I hope that my research will shed new light on this topic.

Data Collection and Analysis:

I will recruit participants from the group of woman attending Hogar, as well as by word of mouth with the help of the directors at Hogar. The desired sample size is approximately 50 participants. I will give the participants the survey with the consent form as the cover sheet (in Spanish) and be available, along with clinic staff, to answer questions about the project in a private location in Hogar. The survey will contain no personally identifiable information. After potential participants sign the consent form, I will leave them alone to complete the survey. If a participant cannot read, I will read the consent form and survey questions to them and record their responses. I will have paper copies of surveys and consent forms, which will be printed at the Institute for Central American Development Studies (ICADS), my supported research site. I will utilize the ICADS facility to store my data materials via a private locker. As I collect surveys from participants, I will enter data into a Microsoft Excel database (stored on a password-protected computer), and I will scan all consent and survey forms to my password-protected personal tablet computer. My project is a quantitative study, so I will prepare charts and graphs of participant responses. I will conduct a descriptive analysis to summarize my data and perform statistical tests (Chi-square and t-tests) as appropriate to examine any bivariate differences. I will also obtain human subjects training before conducting the study.

Timeline (2014):

May 16th: Final pre-departure meeting with Dr. Catherine Satterwhite (Epidemiologist in Preventive Medicine and Public Health) and Dr. Megha Ramaswamy (Sociologist in Preventive Medicine and Public Health)

May 24th: Fly out from GTR in Columbus, MS to Juan Santamaria International Airport (SJO) in San José, Costa Rica and unite with my homestay

May 25th-31st: Spanish and Cultural Immersion/ Site visits to El Hogar de la Esperanza and ICADS

June 1st- June 28th: Administration of surveys and participation in Spanish language classes at ICADS

June 29th-July 12th: Data analysis and management

July 13th- July 19th: Writing and identifying areas of future research/ present findings to ICADS

July 20th: Return to Starkville, MS

Methods

As mentioned previously, I have studied in Costa Rica twice and know the city of San José well. I contacted my previous program director Kat Peters, who is the assistant director at ICADS, where I studied for a semester. She has agreed to establish my family homestay and Spanish courses as well as provide all transportation services, meals, and laundry service while I'm in Costa Rica. She will also provide me with a mentor to assist me in my research efforts. We have already identified a clinic for me to work at this summer called El Hogar de la Esperanza. Students before me have worked at the clinic, and Ms. Peters assured me that they will welcome me to work there this summer as well.

I have also met with Dr. Catherine Satterwhite, Dr. Megha Ramaswamy, Dr. Courtney Huhn, and Dr. Mike Werle to discuss my research design. They have all helped me arrive to a research question and guided me on my research methods. All are committed to helping me see this project through. Additionally, I met with Anne Huffman, in the Dykes Library Research Department, to gain knowledge on appropriate databases to search on humanities and social science topics as well as completed a brief Endnote tutorial. I met with Kyle Stevens of KU IRB, and I have started my IRB application. Status is pending. I have met with Kimberly Connelly in the office of International Affairs to discuss the feasibility and logistics of my travels to Costa Rica. I purchased Rosetta Stone to advance my Spanish speaking skills, and I plan to work with local acquaintances each week for one hour to practice my conversational Spanish language skills. Because I realize that I will need additional funds outside of the Clendening Fellowship, I met with Blair Kidney and contacted Kristi Nicol of Financial Aid and learned that I have an additional \$7,000 plus the summer aid of \$2,000 that I have at my disposal for the summer.

Budget

Round Trip Airfare to San José, Costa Rica	\$913.00
Homestay, transportation, meals, laundry, Spanish courses	\$4,000.00
Miscellaneous	\$300.00
Total	\$5213.00

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ICADS OVERVIEW OF ETHICAL PRACTICES OF RESEARCH AND ENGAGEMENT IN COMMUNITY

ICADS follows the standards of the Belmont Report (autonomy, beneficence, and justice) for research in communities in Costa Rica and Nicaragua. Ethical treatment of research participants is of the highest priority at ICADS. Students must pledge to abide by the following ethical standards when carrying out interviews, surveys, focus groups, or other social science research while at ICADS.

1. Informed Consent

RESEARCH

When conducting an interview or using a conversation for research data collection, you must have informed consent from the individual. This means you must inform the individual of your research intentions and who might possibly view your data before interviewing that individual. You must accept any refusal or declination to be interviewed.

PHOTOGRAPHY

Please ask each individual you intend to photograph before taking any pictures. Be specific about the intended use of the photo. If appropriate, given the norms of the culture in which you are conducting research, get a signed release form. Please do not take pictures for public use unless given permission by the individual in the photograph and the director of your program.

Photographing children. In general it is best to take photos only when the parents or teachers are present and give their approval. Again, if appropriate, use an authorization form in their first language and never assume they know what it says. If you are in an internship or community for an extended period of time, you will likely be granted the permission to take photos of children you meet and/or work with through the Central American cultural value of *confianza*, or personal trust.

2. Compensation

Before offering compensation for participation in a research project to any individual, discuss your plans with the faculty supervisor of your project and the director of your program. In most cases, compensation is not necessary, as ICADS compensates organizations and families for their support of you. Also, individuals whom you interview are agreeing voluntarily to participate in your project and do not expect compensation. Never loan money to anyone in the organization in which you are working or any individual involved in your project.

3. Questions

Be critical of the types of questions you include in everyday conversation, surveys, and/or interviews. Avoid questions that may frighten or intimidate the people you are interviewing (this requires understanding the context of your interviews – in a place where maritime laws are being enforced, a question about property limits might be more sensitive than in a place where such laws are not being currently discussed). Always explain your intentions. Assure confidentiality. For example, if working with a mostly undocumented population, you must always be aware of issues of privacy and law. Whenever possible, review and refine your research questions with your program director and faculty advisor before beginning your field research. You will find that in Costa Rica and Nicaragua, among the communities in which ICADS works, that information that you may not volunteer in an interview does not have the same stigma here. Asking someone how much money they make, for example, does not hold the same stigma in many places in Central America as it might in your community.

4. Confidentiality

If you are discussing sensitive topics that make the individual uneasy, always assure confidentiality and always keep book, research notes or final paper. Keep a private key to the names for your own private use, but do not release those names. Always ask the individual if you can use his/her real name before doing so. In

some cases you may want to use a pseudonym for your research location (village, community, organization) to add another level of confidentiality. Discuss this with your program director and faculty advisor.

5. Culture and Reality

Always be aware of the specific reality of your particular site. This reality may be different from what you would expect, what you are accustomed to, or what you commonly understand. Or it may be very similar to what you would expect. Whatever the situation, there are some general guidelines to follow in order to retain professionalism in a community environment. For example, dress code can become an issue in many environments. It is important to dress in a manner that affirms you as a student with an academic and community-based purpose. Otherwise, you may attract attention that may be perceived negatively or be misunderstood.

Also, age and gender play roles in forming relationships. For example, if you are working with older participants, they may expect you to demonstrate clear respect for them because of their long and often complex histories, yet they may feel they have to be deferential to you because you are college-educated and therefore have a high social/economic position. These relationships of power and respect are sometimes difficult to manage, but you should always keep communication open. Assume good will.

6. Safety

If there is any question about safety (e.g. the neighborhood where your internship or research site is located), try to go to your site with a partner especially at night. Consider going with a fellow student, a member of your host family, or a trusted member of the organization where you are working. Always have the organization supervisor or a staff member present at your site when you are there. Never go to your site alone when confronting a conflict or problem. Ask your program director to accompany you under such a circumstance.

7. Phone numbers

Never give out your phone number or the address or phone number of your host family. You can use the number of your program office if you absolutely must give contact information.

8. Sexuality and Gender Considerations

The guidelines you receive for culturally appropriate behavior in the community and with your host families should apply for your internship or research. Check with your program director on any special considerations you need to be aware of in your particular situation. While cultural norms may vary, certain behaviors are not acceptable. Sexual harassment will not be permitted in any form (although the understanding/definition of sexual harassment will vary from culture to culture, and you need to be sensitive to this). This means that within the context of your host culture, you should refrain from any type of behavior that gives the appearance of sexual harassment. By the same token, we will not permit any type of sexual harassment to be perpetrated on you. At the first sign of a problem please contact your program director so that you can work together to resolve the situation.

Keep in mind that any romantic or sexual relationships you form with people involved in your research or internship (clients, participants, supervisors, interviewees, etc.) may be unethical and/or culturally inappropriate, could negatively affect your ability to conduct your project, and might have negative consequences for the person you are involved with. Please consult with your program director for clarification in this regard if this is likely to become an issue. Many internship placements and community organizations request that student volunteers and researchers refrain from entering into romantic relationships with local people.

9. Working with Children

Consult with your program director regarding cultural, ethical and legal concerns you need to understand when working with children. In general, if you witness any type of physical abuse, neglect, sexual abuse, emotional maltreatment of a child you should report to your program director. You are not permitted to transport children.

10. First Aid

You should learn and follow your organization's procedures for medical emergencies and the administration of first aid. You should wear protective gloves when coming in contact with blood or any type of wound. Take special care around needles or other medical instruments if you are working in a health care situation. It is always best, whenever possible, to allow a school nurse, local health professional, or member of your organization to handle medical and first aid situations.

11. Punctuality and Follow-through

It is important to remember that some of those with whom you may be working (e.g. children, adolescents, abused girls and women) may have abandonment issues. You may trigger negative emotions if you are late or fail to show up when you are scheduled. It is imperative that you prove to them that they can count on you for doing as you promise. In addition, you are a role model, and they will see no reason to follow through with their promises if you do not follow through with yours.

Note: This document was adapted from a document produced by the Pitzer College Community Engagement Center (formerly California Center for Cultural and Social Issues).

ICADS Declaration to Adhere to Ethical Practices of Research and Engagement in Community

Read the document. Place your name, date and signature at the bottom.

1. I will always obtain consent from the participants for any interview/questionnaire/research/evaluation I conduct with them. I will inform them of the purpose of the task. I will respect their decision and not treat them unfairly if they decline to participate.
2. When I ask questions of the participants whether for research or everyday conversation I will refrain from asking any questions which might be construed as intimidating or frightening. I will always explain my intentions and assure confidentiality.
3. I will always obtain consent for photographing, audio taping, or videotaping the individuals. If appropriate, I will get a signed release form - even if the collection of this information is for my personal use. When photographing, audio taping, interviewing, or videotaping children/minors, I will always go to the parents, legal guardian, or school administrator for consent.
4. If these individuals are clients of or participants in a particular organization with which I am working, I will always get permission from the director of the organization before I take any action related to my research.
5. If I keep field notes or other written records of my interactions, I will refrain from using real names, except for key informants who have consented to my use of their names. I may choose to create a key to the names, which I will keep confidential.
6. I will arrive at the organization or research site at the time I am scheduled. If there is preparatory work to be done for the meeting, I will complete that work before the meeting or arrive early enough before the meeting to make necessary preparations.
7. I will dress in a manner appropriate for the program, organization, or community with which I am working. In addition, I will be sensitive with regard to dress and attitude to not in any way demonstrate disrespect to its members, clients, or collaborators of that organization.
8. I will always use respectful language at my site and in my research interactions.
9. I will follow all safety guidelines given to me by the program director and organization supervisor, including precautions related to travel to and from my site.
10. I will ask for and follow safety, first aid, and other emergency procedures from my site.
11. If it is necessary to give a contact number to others in relation to this project, I will provide the number or email of the program office. I will not give out my personal contact information or that of my host family.
12. If I feel I am the recipient of any form of harassment in the organization with which I am working or I am confused about any behavior or language that is directed at me, I will consult with the program director and organization supervisor immediately.
13. If I witness any type of abuse or harassment, or behavior that I am not sure about, I will consult with my program director immediately in order to better understand the situation, and if necessary, resolve or report a problem.

I have read, understood, and agree to follow these ethical practices of research and engaging in the community.

Signature _____ Date _____

Print Name _____

Note: This document has been adapted from the original produced by the Pitzer College Community Engagement Center (formerly the Center for California Cultural and Social Issues).

Questionnaire

Note: Once I receive IRB approval and have a final questionnaire, I will translate the questions into Spanish before departure. This survey is a draft. Also, my consent form will be a cover page to the survey questions.

Instructions: Please check all that apply.

1. What is your sex?

A. male B. female C. neither D. no response

2. How would you describe your gender?

A. male B. female C. transgender/transsexual D. neither E. no response

3. How many sex acts have you had in the last week, for example, vaginal, anal sex, or oral sex?

A. 0-5 B. 5-10 C. 10-15 D. 15-20 E. more than 20

4. When you engaged in vaginal or anal sex in the last three months, how often did you use a condom?

A. never B. less than half of the time C. more than half of the time D. always

5. The last time you had sex, did you use a condom?

A. yes B. no

6. Have you ever had an unintended pregnancy, one that was unwanted, unexpected, or a surprise?

A. yes B. no

7. Do you have sex with A. men B. women C. both

8. Do you engage in A. oral sex B. vaginal sex C. anal sex D. all of the above

9. How often to you go to the clinic for your physical exam?

A. once a week B. once a month C. once a year D. hardly ever

10. Have you ever had a sexually transmitted infection?

A. yes B. no

11. Have you had a sexually transmitted infection in the last year?

A. yes B. no

12. Do you think the government regulation of sex work is good?

A. yes B. no C. not sure

13. How is government regulation of sex work good?

- A. Fee healthcare B. Less violence C. Less Disease D. Less stigma
E. More jobs

14. Have you ever experienced violent behavior from a customer?

- A. yes B. no

15. What kind of violent behavior?

- A. Rape B. Physical abuse C. Verbal abuse

16. Are you

- A. Single B. Married C. Single with children D. Married with children

17. What is your highest level of education?

- A. Grade school B. Middle School C. High School D. College E. Graduate School

18. How long have you been a sex worker?

- A. A few weeks B. A few months C. One year D. A few years E. More than 3 years

19. How much money do you earn a week from sex work?

- A. \$50-\$100 B. \$100-\$200 C. \$200-\$300 D. \$300-\$400 E. \$500 F. More than \$500

20. How do you charge customers?

- A. Based on type of sex act (vaginal, oral, anal) B. Condom use C. Known diseases

21. Did someone force you to become a sex worker?

- A. yes B. no

22. Why did you become a sex worker?

- A. money B. independence C. empowerment D. other

Consent Form

This is a research project exploring the quality of healthcare of sex workers under government regulation. I hope that the results of this study will add to future research on sex work in the United States. All responses are confidential, and participation is voluntary. If you have any questions or concerns about your participation in this study, please contact me at tmanning@kumc.edu.

I have read this form and understand its contents.

Participant Name

Participant Signature

Date

IDENTITY AND OPTIMISM IN ADOLESCENTS WITH CANCER: A VISUAL PERSPECTIVE
Clendening Summer Fellowship Proposal
Errin Mitchell

Introduction:

Cancer during adolescence is a life-changing event for both the adolescent and their family. Normally, adolescence is a time for movement towards independence and acquiring skills to carry out adult relationships, and it is critical time for development of a positive self-identity. However, the effects of cancer may make some of these developmental tasks more difficult to achieve. This project aims to explore the narratives of adolescents with cancer in an effort to understand how cancer impacts the development of an adolescent's self-identity. When examining the development of self-identity, both self-concept and self-esteem must be considered. Because research has shown that the development of self-esteem can impact optimism in adolescents (Puskar et al., 2010), this project will examine how the development of identity in adolescents impacts their optimism levels. Finally, elements of photovoice will be used in order to gain a novel and unique perspective from the adolescents. Cancer during adolescence is filled with complex challenges and changes; and this study would allow for an invaluable new perspective that would lead to increased understanding and appreciation for the intricacies of adolescent cancer.

Background:

Adolescents with cancer face unique challenges, as they are undergoing diagnosis and treatment in addition to the developmental adjustments and difficulties inherent in their life-stage (Li, Lopez, Joyce Chung, Ho, & Chiu, 2013). Day-to-day routines, relationships, major milestones, and self-esteem are all threatened by cancer (R. L. Woodgate, 2005). Previous research has found that although having cancer does not necessarily lead to difficulties in adjusting and developing, it does put adolescents at increased risk for psychosocial problems (Gregurek, Bras, Dordević, Ratković, & Brajković, 2010). There has been increased attention to the influence cancer can have on an adolescent's sense of self since adolescence is a critical period for the development of a positive self-identity. Past research has suggested that cancer universally changes the way adolescent survivors view themselves, and that change can be both positive and negative (Anholt, Fritz, & Keener, 1993; Smith, Ostroff, Tan, & Lesko, 1991; Zebrack & Chesler, 2001). Other research has found that children and adolescents with cancer experience a negative impact on their self-concept due to their illness and its treatment. However, much less research has been done looking at the narratives told by the adolescents themselves. Furthermore, it is important to consider how the development of self-esteem will impact optimism. Self-esteem specifically refers to the negative or positive value ascribed to the self-concept (R. Woodgate & McClement, 1997). If cancer impacts the development of self-esteem in adolescents, it is important to understand optimism in adolescents with a serious illness, such as cancer, given that optimism is known to be an important predictor of health outcomes (Hinds, 1988).

Personal Motivation:

When I tell people I am interested in pursuing a career in pediatric hematology/oncology, I often get a response of, "Ooh, that would be a really sad job." This response is often disconcerting to me because I have never it that way. Sure, the idea of sick children is not exactly happy, and there is a morose quality to any job that involves death, but that is part of being a doctor. I find that working with this population can be incredibly gratifying. There is a resilience often found in youth that is much more rare in adults. For them, the world is still a magical place with discoveries to be made and adventures to be had, which is remarkable to see in the face of such great adversity. This is why I have continuously been drawn to pediatric hematology/oncology (beyond just being fascinated by the pathology of these diseases).

During college, I focused my studies on health psychology. I was intrigued by the complex interactions between the mind and the body and how delicately intertwined the two are. I quickly became involved in research area, eventually writing my honors thesis on how genetic polymorphisms relate to stress reactivity. This project would be an ideal opportunity to pursue psychosocial research as a medical student and a wonderful chance to combine my interests in psychology and pediatric oncology.

I was drawn to this specific project after spending a year working with adolescents from an underserved background. I have been able to see how adversity can impact an adolescent's capacity to figure out who they are and how they feel about their identity. Given my interest in pediatric oncology, I have become very interested in the psychosocial impacts cancer can have on adolescence. Furthermore, I want to use photovoice as a way to give participants control. This is a population that can often feel powerless to their illness, and I would love to see the results of giving them the control to image their world. Given the psychosocial complexities associated with adolescents with cancer, this study would allow for new insight into a nearly unimaginable way of being.

Description:

Specific Aims	Methods
<ol style="list-style-type: none"> 1. To investigate the narratives of adolescents with cancer, specifically their development of identity 2. To assess their levels of optimism and how that relates to the development of identity 	<ol style="list-style-type: none"> 1. Use photovoice to guide the narratives and elicit a new perspective 2. Conduct semi-structured interviews of adolescent cancer patients

My project intends to examine the following questions:

1. How do adolescents with cancer develop their identity?
2. In what ways does having cancer impact the development of an adolescent's identity?
3. Does the impact on the development of identity affect optimism in the adolescents?

Specifically, this project intends to:

- Use photovoice to elicit adolescent perspectives
- Explore the narratives of adolescents with cancer to better understand their perspective
- Examine the self-identity amongst adolescents with cancer
- Measure the levels of optimism in adolescents with cancer at a single time point
- Identify any common themes and patterns in the development of identity amongst adolescents with cancer

As a secondary aim, this project intends to begin to understand how the levels of optimism relate to the development of self-concept.

For my project, I plan to use photovoice as a part of the data collection. Photovoice is an exploratory research method that helps to give insight into how a population conceptualizes their situation using images (C. C. Wang, Yi, Tao, & Carovano, 1998). Typically in photovoice, groups of people are given cameras to record their reality and engage with researchers to foster understanding and advance change (C. Wang & Burris, 1997). Previous photovoice studies have shown that this method can be valuable in capturing aspects of life that traditional surveys cannot (Catalani & Minkler, 2010). Using this tool in my study will allow me to gain information personalized to the individual participants that would be difficult to obtain solely with traditional research methods.

Timeline:

March/April: Develop/Finalize set of interview questions and submit for IRB approval.

May: Begin recruiting participants at Children's Mercy Hospital upon approval of the IRB. At time of recruitment, participants will be consented and given cameras and instructions. Their interview will be scheduled during the 8-week project timeline.

June 2 –July 25 (8-week project timeline): Continue recruiting participants. Conduct patient interviews. Code interviews and analyze data.

Methods:

For this project, I have been in contact Joy Fulbright, MD, and Kristin Stegenga, PhD, RN, who have agreed to mentor me. Dr. Fulbright is a pediatric hematologist oncologist at Children's Mercy Hospital who specializes in the clinical treatment of adolescents and young adults with cancer. Kristin Stegenga is a research nurse at Children's Mercy in the Division of Hematology/Oncology/Bone Marrow Transplantation. Her research experience primarily lies in studying the narratives and quality of life in adolescents with cancer and sickle cell disease. She also has experience with using photovoice with adolescents. Both are enthusiastic about this project and have been instrumental in the development of the project thus far.

This project will focus on patients between the ages of 12-18. Patients must have current cancer diagnosis that was received at least 6 months prior to recruitment. This is to ensure that they have had time to process their diagnosis and how it relates to their self-identity. My goal is to have at least 10 participants complete the study by the end of the

summer. I will be recruiting patients from Children's Mercy Hospital in Kansas City. Patients who come in for a scheduled visit will be given details of the study in age-appropriate terms and asked to participate. Those who consent will be given cameras to take photos and scheduled for an interview during their next hospital visit. If their next visit is after the end of July, arrangements can be made to schedule an earlier interview. Patients will also be asked for email and phone number, and I will confirm if it is ok to text/email them reminders. I will also use their email address to send them an invite to Dropbox to upload their photos prior to their next interview. As an incentive to completing the study, patients will be allowed to keep the camera after the study is over. At the time of consent, participants will receive instructions on how to use the cameras. They will also be encouraged to take photos that represent who they are and their life with cancer. If they take photos of others, they will need to obtain a signed photo release from that person or their parent (if they are under 18). I will later email them text instructions for using Dropbox to upload their photos if they are able. I will email or text them a reminder once a week about taking or uploading the photos. Participants will also be asked to bring the camera to the interview in case they forget or are unable to upload the photos. I will send a text or email the day before the interview to remind them to bring the camera and photo releases.

At their next appointment, patients will participate in a semi-structured interview, with the photos used as a way to guide the interview. Participants will be asked questions about how they view themselves, their attitudes towards themselves, the qualities they attribute to themselves, and the value they place on their attributes. Photos taken prior to the interview will be used to guide their answers and elicit a visual perspective on their identity. Each photo will be assigned a number to which it will be referred throughout the interview in order to insure that later, during analysis, I will be able to know what photo they are sharing information about. For each photo, I will ask participants to tell me about the photo, which further prompts such as "How does this represent you or your life?" if necessary. The interview will consist of open-ended questions. Examples of questions that might be asked include:

- Some kids with cancer have told me that having cancer makes their day-to-day lives different. What has it been like for you? How does this photo represent your day-to-day life?
- What were you feeling when you took this photo? Do you feel that way frequently? Has having cancer changed the way you feel?
- Do you think cancer has changed you? If so, in what ways?
- What do you feel are your positive qualities? What things would you want to change about yourself?
- What are some things in the future you're looking forward to?

At the end of the interview, participants will fill out demographic information, as well as a survey measuring optimism. To measure optimism, I plan to use the Life Orientation Test-Revised (Scheier, Carver, & Bridges, 1994). Each interview will last approximately 30-60 minutes or as long as it takes to discuss all the participants photos. Afterwards, interviews will be transcribed using a professional transcription service. I will then use qualitative content analysis to analyze the data. This will be done by coding the text to identify patterns and themes. When analyzing the interviews, special attention will be paid to

themes of optimism and self-esteem. Then, the data will be further analyzed for correlations between patterns of optimism in individual participant's photos and narratives and the measured levels of optimism.

Budget:

Cameras – 15 cameras at \$59.99 each + Tax (See Appendix)	\$978.75
Transcription Services – \$1/min*	\$1,000.00
Living Expenses (Mostly consists of food/groceries)	\$500.00
Total	\$2,478.75

Should my actual expenses surpass that of my estimated budget, I understand that I am responsible for any expense exceeding the \$2,500 stipend.

*Note: I am budgeting for each interview to take at least 60 minutes, plus some room for participants to talk more.

Mentors:

Joy Fulbright, MD

Kristin Stegenga, RN, PhD

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Clendening Summer Fellowship Research Proposal 2014

Measuring Health-Related Quality of Life for Summer Therapy Campers at Bay Cliff Health Camp

Sarah Scrafford

Introduction

Over the past several decades, clinicians have begun to consider measures of health-related quality of life (HRQL) as an essential component to patient care and treatment evaluation¹. It is increasingly considered to be a reliable method of gauging treatment effectiveness and quality of care for a variety of patient groups. It is currently being used by both the World Health Organization (WHO) and Healthy People 2020 to measure comprehensive health including its physical, emotional and social dimensions in a general population^{2, 3}. It is also used to measure quality of life in patients with specific disease states or long-term disabilities, focusing on areas of function related to chronic illnesses (for example, measuring gross and fine motor functioning in children with cerebral palsy⁴). My proposed Clendening summer research project focuses on the standardized quantification of HRQL measures at Bay Cliff Health Camp, a seven week therapy camp that seeks to improve the quality of life of children with physical disabilities through therapy sessions, recreation and fellowship with peers.

Background

I became interested in this topic after working at Bay Cliff Health Camp's Summer Therapy Camp for several summers. Bay Cliff is located in the Upper Peninsula of Michigan and functions as a therapy and wellness facility throughout the year. The camp was established by Dr. Goldie Cornelieuson and Elba Morse, a nurse supervisor, during the Depression for children who were poorly nourished due to the impoverished conditions of the time. The camp transitioned to a therapy camp during the 1940's when polio left many children in the Upper Peninsula unable to walk and in need of physical rehabilitation. While polio became less common over time, Bay Cliff continued to provide therapy to children with a wide range of physical disabilities. Today, it provides children with a variety of therapies including physical therapy, occupational therapy, speech therapy, hearing therapy, and vision therapy depending on their goals toward independence. Recreational activities such as camping, hiking in the woods, and taking a walk or ride down the beach trail to Lake Superior continue to be an integral part of how Bay Cliff seeks to incorporate therapy into everyday activities.

I spent three full summers over the past five years working at Bay Cliff. The first summer I worked at Bay Cliff, I worked as a housekeeper and laundry aide. I was entering college in the fall and had not decided that I wanted to go into a health-related field after I graduated. Bay Cliff introduced me to a type of healthcare that was hands-on, personalized, and encompassed the needs of the whole person. During the second summer I worked at camp, I worked as a counselor for four girls, aged 6 to 10, each with a different diagnosis and each with different goals for what they wanted to learn at camp. One of my campers transitioned from her wheelchair to a walker after a spring surgery; another camper learned to tie her shoes; one worked on putting on her

ankle foot orthotics without assistance while another learned to brush her hair and pull it into a ponytail by herself. Each of them had goals focused on improving their independence, regardless of their diagnosis. I worked exclusively with the teen campers for my third full summer, where I learned that the social dimensions of a camper's life are essential components to their quality of life. While an individual's physical capabilities strongly influenced therapy goals and methods, they are not the only factors that affect a patient's quality of life.

My decision to enter medical school was strongly influenced by my time working at camp. It continues to influence my interests in specialties, including my interests in pediatrics as well as physical medicine and rehabilitation. Designing my research project around the question of HRQL for campers at Bay Cliff serves two purposes. First, it would allow for a better understanding of the multidimensional aspects of camper's quality of life; it could also provide early quantitative measurements of potential benefits and costs to the six week therapy program. Secondly, it would also help me to professionally develop my understanding and skills of the therapeutic approaches to working with individuals with physical disabilities.

Description

My research proposal will be carried out before, during and after Bay Cliff's Summer Therapy Camp which runs from June 14 until August 2. My timeline is coordinated with this schedule, although some adaptations will be made to accommodate my academic schedule.

In order to evaluate health-related quality of life measures, my project will be using a group of surveys called the Child Health Questionnaire (CHQ)⁵. The surveys are designed and normalized to be administered to children ages 5-18. It measures physical and psychosocial areas of quality of life, which are broken down into 14 major categories. I will be administering two form types: parental and child self-report. The parental form, CHQ-P50, consists of 50 questions pertaining to their perception of their child's HRQL and can be administered to parents of children age 5-18. The child self-report is for children age 10 and older; it is 87 questions and pertains directly to their HRQL.

There are several reasons for choosing to use this questionnaire. First, among similar surveys addressing research questions pertaining to pediatric HRQL, it is cited frequently in published articles and is used worldwide to measure HRQL in a various patient populations. Unlike many other measures of HRQL, it is also preferable because it is not disease-specific. Bay Cliff has a diverse group of campers every year and the survey needs to be able to accommodate the complexity of their health impairments, strengths and goals that they bring to camp. After reading through sample questions of the CHQ parental and self-report surveys, these questions cover a variety of topics that are pertinent to campers at Bay Cliff.

Along with the survey's qualities, CHQ also allows for scoring, analysis, and comparison with standard values provided by the survey administrators. This will allow for straightforward and fruitful analysis of the data I will be collecting. I believe this will be advantageous for two reasons. First, it produces a greater opportunity for meaningful quantitative data to be collected and then potentially reported in publication. Second, it provides a unique opportunity for Bay Cliff to analyze and evaluate their strengths in providing therapy while also determining

potential areas of HRQL that they can address more fully in future summer therapy camp sessions.

Finally, both versions of the survey allow for a unique research opportunity for Bay Cliff. It allows for a larger age range of campers to be included in the process (the parental form included children age 5-18 while the child self-report version includes children age 10-18). It also sets a groundwork for future analysis if the survey is considered to be useful in analyzing and improving therapeutic methods and goals for subsequent years. Many campers return year after year, with approximately 70% of total campers each summer being returners, allowing both child and parent to see changes in themselves or their children. There is considerable anecdotal evidence that campers benefit from the therapy they receive while at Bay Cliff which is reported by campers, their parents, and their health care providers. In addition to anecdotal evidence, measurements of HRQL would allow for a greater understanding of what role a camp like Bay Cliff currently serves in providing therapy as well as what role it could serve for future campers.

Timeline:

March- Licensing approval has already been attained through HealthActCHQ. Fees would be paid to gain access to the surveys. I would spend this month becoming familiar with the surveys and Scoring and Interpretation manual.

April- Before camp begins, a packet of information is sent out to parent. I would like to draft and send a letter explaining the project and its goals to the parents. The parental survey will not be sent out until after camp has begun.

May- I will be driving up to camp so that I have access to a car for the summer. My schedule for arriving at camp depends upon camp needs and will be spent doing work for personal development (shadowing the camp physician Dr. Michael Nidiffer in his private practice, working at the Autism camp and Down Syndrome Camp hosted by Bay Cliff). The six weeks spent for the Clendenen Summer Fellowship will take place during the Summer Therapy Camp during June.

June through July- All staff will be present for orientation starting June 8. Campers arrive June 14 and remain at camp until August 2. I will remain at camp until I need to return to Kansas City for leadership commitments for M1 orientation week (July 24).

Parental forms will be distributed by mail during the week of June 16-20. They will be sent with a stamped return envelope to encourage completion and return. Potential monetary incentive, such as having name entered into a gift card raffle, for returning the completed forms will be considered (pending IRB approval).

During camp, I will conduct interviews for child self-report questionnaire. Due to therapy and activities scheduling, I will coordinate camper interview with their therapists and counselor. I will be interviewing approximately 70-80 campers age 10 to 18. I will conduct my interviews within the first three weeks after campers arrive (June 16-July 5) and will begin analysis on data

collected from both parent and child surveys during my final three weeks (July 6-24). I will finish any remaining analysis when I return to Kansas City.

Methods

I will be working with the staff at Bay Cliff Health Camp while conducting my research. I have spent five summers at camp and am familiar with the camp's rules, mission, and schedule. I have received permission from the Camp Director Mr. Tim Bennett to carry out this project under the direction of Miss Christy Osborn, PT, DPT, and Therapy Coordinator at Bay Cliff. Miss Christy and I have been in contact with one another concerning this project since December and she will continue to mentor me during the summer while I am carrying out my research.

I will be driving to camp with my personal vehicle, allowing me access to transportation throughout the course of the summer. My accommodations will be on camp, including housing and food. All staff including nurses, therapists, activity coordinators, auxiliary staff and counselors (except for a few members of auxiliary staff with families nearby) reside on camp grounds.

My daily schedule will be influenced by the camp's schedule for the day. I will be conducting interview with campers throughout the first three weeks of camp and analyzing data throughout the last three weeks of my time at camp. Depending on the camper's communicative ability, the interview should take between 30-60 minutes. Because some campers are unable to write, read or speak without the use of sign language or an assistive communication device, I will be interviewing all campers. Sign language instructors and speech instructors will be used when needed.

In addition to the data collection portion of my project, I will also be working with the therapists in their daily therapy sessions with campers. I have been offered the opportunity to work in a unique inter-professional team of health professionals.

I will also be using the time to spend time with three physicians associated with Bay Cliff. Dr. Carl Eiben, MD, is a Physical Medicine and Rehabilitation (PM&R) physician who practices nearby at Marquette General Hospital. He also participates within camp during Rehab Team Meetings where a camper is evaluated by the whole team of individuals responsible for the camper (including therapists, counselors, the camp orthotist, and the PM &R physician). Dr. Mike Coyne is a retired PM&R who has offered to help with the project if needed. Dr Mike Nidiffer is the camp pediatrician who visits camp twice a week in the health clinic on camp.

Budget

- **Gas**
860 miles- KC to Bay Cliff, MI via Minneapolis (rest stop)
\$0.52/mile X 860 miles = **\$447**
Return trip = **\$447**
- **CHQ Liscencing Fee** = **\$350**
- **Supplies for camp (food, toiletry, camping equipment)** = **\$75**
- **Parental survey completion/return incentive (gift card raffle)** = **\$150**

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Comments:

I am applying for a Clendenen Summer Fellowship at the University of Kansas School of Medicine as a first year student. I would like to do research at Bay Cliff Health Camp, a therapy camp for children with disabilities. If I do not receive the fellowship grant, I would still like to carry out the research with the camp administration, at which point it would be unfunded research.

Research State Date: 05/2014

Research End Date: 08/2014

Additional

Languages(s):

Condition-Specific

Survey(s):

Desired Survey(s): CHQ-PF50: English (US)

CHQ-CF87: English (US)

Stories of Health in Rural Appalachia

DEVELOPING AN ANTHOLOGY OF CONTEMPORARY
ART, POETRY AND FICTION BY PEOPLE FROM RURAL
APPALACHIAN COMMUNITIES

Andrea Sitek

CLENDENING FELLOWSHIP PROPOSAL | FEBRUARY 17, 2014

Introduction:

The people of rural Appalachia face a disproportionately high prevalence of poor health, including a high percentage of individuals who suffer from diabetes, heart disease, stroke and cancer. Additionally, they encounter many external obstacles to improving their health status; they struggle with a health professional shortage, high poverty levels, high prevalence of drug addiction and limited access to healthy food and clean water. The coal-mining industry contributes to the poor health of rural Appalachia. However, many people are unwilling to divulge their understanding of the coal industry's effect on their health out of respect for the aspects of their culture and familial history that are closely intertwined with the coal industry. Sometimes, what is difficult to vocalize is easier expressed through visual art, poetry and fiction. I want to create an anthology of visual art and literature that reflects the struggles and triumphs people of rural Appalachia experience in maintaining their health and wellness today.

Background:

Growing up in a small Kansas town and witnessing first-hand how my rural community changed over time sparked my interest in other rural communities across the United States. Throughout my undergraduate career at the University of Kansas, I developed a fascination with the changing culture and environment of rural Appalachia. I created alternative spring break trips to Whitesburg, KY, and Appalachia, VA during my sophomore and junior years of college. I wanted to allow the participants in my alternative spring break the opportunity to learn how coal mining has shaped the culture and socioeconomic environment of rural Appalachia. We met with local activists and community members to better understand the struggles rural Appalachian communities face today and learn about how local people are addressing these issues at the grassroots level. While I was in Kentucky and Virginia, it became clear to me that many Appalachians are concerned about how poverty, limited access to healthcare, and environmental changes related to coal-mining have affected the health of their families and fellow community-members.

After returning to Kansas, I continued conducting my own research on the unique challenges people face in maintaining their health in rural Appalachia. However, due to a strong sense of pride in the hard labor their family members and ancestors poured into the coal mines, as well as a fear of speaking ill of the powerful coal companies, issues related to coal mining, including health concerns, can be sensitive subjects for many people of rural Appalachia. Because of this, it can be difficult for Appalachian's to freely tell their stories of health, especially to an outsider like me. This is why I want to use art and literature to access Appalachian peoples' unique stories of and concerns over health.

I studied English literature in college, because I am interested in the many ways people tell their stories. I want to utilize the skills I developed as an English major to access the stories of health and healthcare in rural Kentucky and Virginia through art and literature. I will use these stories, as well as the stories I hear by meeting with and talking to activists and physicians in the region, to produce a short anthology that is a compilation of contemporary art, poetry and fiction related to healthcare in rural Appalachia. I hope that it inspires critical reflection on the state of healthcare in the U.S., as well as reflection on the strength of community action and solidarity.

Description:

I will visit rural Kentucky and Virginia at the start of the summer (June 1-21) to collect stories, information and art, and then use the rest of the summer to create an anthology of art, poetry and fiction

For instance, a page in the anthology might include a piece of art like this one:



This above image is a small section from a larger poster created by the Beehive Collective called “The True Cost of Coal.” The illustration depicts a frog with back pain caused by working at the mine, a mother frog in a garden who has had her gall bladder removed (visible scar) and cannot grow healthy food to feed her family due to the lack of access to clean, healthy water (black water flows from the tap). In the bottom right-hand side of the image, a frog is paying a mule for Oxycontin pills and bottled water.

Throughout the anthology, I would refrain from directly interpreting the art for the viewers, to avoid putting words in the mouths of the artists and writers. Instead, I will include information I’ve gathered through research on the state of health and healthcare in rural Appalachia or interviews that I’ve acquired by meeting with community members and physicians to accompany the images. The goal of including this other information would be to facilitate informed interpretation of the art, poetry and fiction on the part of the readers of the anthology.

Timeline:

A large portion of my summer will be spent conducting research online and maintaining contact with organizations that can provide me with access to art, poetry and literature from rural Appalachian’s online. I will, however, spend three weeks in rural Kentucky and Virginia, meeting with physicians, scholars, activists and historians.

- | | |
|--------------------|---|
| <i>March 8- 16</i> | I will conduct research to acquire a more complete picture of the unique struggles people of rural Kentucky and Virginia face with regard to health and healthcare. |
| <i>June 1</i> | Drive to Hazard, KY. |
| <i>June 2-7</i> | I will meet and volunteer with physicians and healthcare providers at the Center of Excellence in Rural Health in Hazard, KY. |
| <i>June 8</i> | Drive to Whitesburg, KY. |
| <i>June 9-16</i> | I will meet with and shadow physicians in Whitesburg, KY. I will also use this time to meet with historians, activists and community members through |

Mountain Justice, a regional activist network, and Appalshop and Appalachian Media Institute, an organization that has a rich collection of art and media created by local people.

June 17

Drive to Appalachia, VA

June 18-20

I will meet with family physicians in Appalachia, VA. I will also spend an afternoon with AmeriCorps VISTA volunteers at Southern Appalachia Mountain Stewards.

June 21

Return to Kansas City.

June 21-July 28

I will continue organizing the anthology, conducting research, and maintaining contact with the organizations I worked with in Kentucky and Virginia. I will send them each a completed copy of my anthology to read (and correct if necessary) before the summer ends.

Methods:

A large portion of my work for this project will consist of independent research that I conduct online and through the interlibrary loan at KUMC. However, I will not be able to create the anthology without assistance from a number of organizations and physicians. I have been in contact with several individuals who I worked with when I planned the alternative spring break trips to Whitesburg, KY, and Appalachia, VA, (e.g. Elizabeth Barret and Dave Cooper), and I am currently reaching out to physicians and other community members. Here is my list of contacts as of now:

Elizabeth Barret

Director of Appalshop Archive

Appalshop and Appalachian Media Institute

Elizabeth Barret and I have communicated about my interest in utilizing the archive of Appalachian media and art at Appalshop.

Dave Cooper

Director of Mountaintop Removal Roadshow

Mountain Justice

Dave Cooper helped me organize the alternative spring breaks when I was an undergraduate student, and I have contacted him about helping me with this new project. He does a lot of work with community members and travels around the U.S. teaching people about the effects of mountaintop removal on rural communities.

Ralph Fugate

Southeast KY Regional Coordinator

Center of Excellence in Rural Health

Hazard, KY 41701

I will work with Ralph Fugate to set up a volunteering and shadowing experience at the Center of Excellence in Rural Health rehabilitation center in Hazard, KY. This will allow me to meet with

physicians and healthcare providers who work in Hazard, KY, and talk about unique problems that rural Kentuckians face as well as the ways the Center of Excellence in Rural Health addresses these issues.

Matthew Hepler

Southern Appalachian Mountain Stewards

511 Main Street

Appalachia, VA 24216

I worked with SAMS during one of my spring break trips, and I plan on meeting with them mainly to discuss the effects mountaintop removal strip mining has had on the health of rural Appalachians.

Mountain Comprehensive Health

Whitesburg Medical Center

226 Plaza Lane

Whitesburg, KY 41858

606-633-4871

I will volunteer with and shadow physicians who work at Mountain Comprehensive Health to learn about their efforts to provide comprehensive care to the community members of Whitesburg, KY, and the difficulties they face in providing care in a rural community. Additionally I want to discuss that they provide personalized care based on the unique health problems of the Whitesburg population, like Black Lung.

Dr. Marlene Bielecki, M.D.

Family Medicine

226 Plaza Lane

Whitesburg, KY 41858

606-633-4871

I will meet with Dr. Bielecki to shadow her and talk to her about what she thinks are the main challenges for rural Appalachian communities with regard to health maintenance and healthcare access. In addition, there are several organizations that I plan on maintaining contact with via email only.

These organizations include:

1. Outta Your Backpack Media: a youth-based media group designed to counter misrepresentation in the media. Email: Obym.org
2. Aurora Lights: an organization that brings together people with different talents who have a shared interest in creating a multimedia representation of history and culture in Appalachia. Email: auroralights.org
3. Beehive Collective: an art collective that has created large works of art about coal-mining and resistance in Appalachia. Email: pollinators@beehivecollective.org

Budget:

My budget exceeds the Clendening Stipend by \$330, but I have budgeted my spring semester loan money so that I will have \$1,000 left over to use during the summertime to supplement the stipend.

Kansas City	June 1-July 28
-------------	----------------

June/July rent	\$800
June/July utilities	\$300
July food	\$200
Total	\$1300
Kentucky/Virginia	June 1-June 21
Gas (~1500 mi)	\$180
Food	\$200
Lodging	\$850
Extra	\$300
Total	\$1530
Summer Total	\$2830

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**Clendening Summer Fellowship Proposal
Spring 2014**

Viktoriya Tulchinskaya

**“An Analysis of the Influence that Psycho-socio-cultural Factors Play in a Patient’s
Experience with Palliative Care in Paris, as Related by Their Healthcare Team”**

*Special thanks go to Dr. Deon Hayley and Dr. Lindy Landzaat
from the Department of Palliative Care
for their invaluable help with this proposal,
for teaching me about the field of Palliative Care,
and for helping to finalize this project.
Deep thanks also go to Dr. Bruce E. Hayes
from the Department of French and Italian at KU
for his help with the material composed in French.*

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Introduction

Following a W.H.O. study in 2000 that analyzed 191 countries' health care systems, France emerged as the highest-ranked health care system in the world with the U.S.A. trailing behind in spot 37 (Shapiro, 2008). I wish to travel to Paris, the largest city in France, in order to study the French—specifically Parisian—people's experience with the health care system. The specific field that I hope to examine is Palliative Care; it is a specialty that encompasses care of patients from many different backgrounds with one (unfortunate) unifying factor: they are all terminally ill. However, from my observation of the patients that are treated by the Palliative Care Service at KU Hospital, I discovered that patients' physical and mental status can many times be incompatible with receiving an extensive interview about their experiences. Thus, my project will focus on interviewing and observing the health care team—the doctors, nurses, therapists, and other professionals—that have extensive, direct contact with patients and their families during this particular stage in patients' care. The specific research question that I hope to answer at the conclusion of my project is: according to patients' healthcare professionals, what are the psycho-socio-cultural characteristics of patients receiving Palliative Care in Paris that predispose them to have a positive end-of-life experience?

Background

My interest in the French language began as early as elementary school when, in fifth grade, I began learning French with my classmates. As my knowledge of the language grew throughout middle school and high school, I became intrigued with French culture as well. I decided to minor in French during my undergraduate education at KU and learned more about the language, culture, and history than all of my previous years of study combined. At the same time, my passion for medicine had already blossomed. While I was knee-deep in science classes, my *Modern French Culture* and *Health Psychology* courses piqued my interest in French medicine and the French health care system. After watching a PBS FRONTLINE documentary titled "Sick Around the World" in my *Health Psychology* class, I became fascinated by the structure and success of the French health care system. The system was not without flaws, but the French philosophy on health and illness was more in stride with my own values than the philosophy of the U.S. This piqued my interest to explore this particular system of healthcare.

While studying to earn my French minor and Pre-Medicine concentration, I also decided to major in Psychology. Learning about individuals' perceptions and experiences with health and illness seemed to me to be equally as important as learning about the treatments of those illnesses. In this way, my studies in Psychology and French drew me to medicine more than any of my required Chemistry or Physics classes ever did.

Upon entering medical school, I explored as many opportunities as I could during my first semester. I serendipitously stumbled upon a fantastic event in October 2013 hosted by the Osler Society of Greater KC titled "The Ethics of End of Life Care." The event featured a panel of three individuals: a physician that specialized in Internal Medicine and Palliative Care, the CEO of KC Hospice and Palliative Care, and a columnist for the Presbyterian Outlook and Catholic Reporter. Medical students from KUSOM and UMKC as well as retired physicians

were in attendance and asked questions of the panel relating to the ethics of illness, death, and dying. The evening brought to my mind many questions that I had been pondering for a long time: how does one best treat a patient that has a terminal illness? What support is important for such a patient? What role does the family play? Are POA's and living wills a commonplace document for such a population? How should physicians and healthcare workers address the topics of "death" and "dying" to patients that have less than 6 months to live? Why are such topics even still taboo? Most important, however, I wanted to know: what distinguishing characteristics exist between patients that have a positive perspective on death and those that die in a way that is contrary to what they would have wanted? When I asked this question to the panel, there was silence for almost thirty seconds after which the physician on the panel finally spoke and said, "That is a good question." At that moment, I knew what I wanted to research for my Clendening Summer Fellowship. I wanted to travel to the country with the best health care system in the world, observe the health care that they provide to their seriously ill and dying patients, and discover—if I could—why do patients' experiences with death vary so greatly? More specifically, however, I wish to discover: what gems of insight can I glean from the health care professionals in France so that I can better care for my future patients domestically? Lastly, if I am lucky, I hope to discover some knowledge that will allow me to grow in accepting my own mortality which, I feel, is an important concern for all physicians to address.

Description

After researching the different clinics, hospitals, and healthcare administrative offices that provided Palliative Care to patients in Paris, I compiled an extensive list of 69 different locations where I could potentially conduct my research. Following the first wave of emails that I sent out, I received three very enthusiastic replies from three different Parisian hospitals (See Appendices C and D for confirmation of the correspondences). With such enthusiasm to back my project, I arrived at the following timeline. My plan is to divide my visit to Paris between five medical locations: Necker Enfants Malade Hospital and the University of Paris under the supervision of Pr Marcel Louis Viallard, Cognac-Jay Hospital under the supervision of Patricia Le Chene, and National Resource Center for Palliative Care and HAD Home Hospitalization under the supervision of Dr. Marie Odile-Frattini. At each location, it is my plan to spend the entire workweek visiting patients with the medical professionals, observe the care provided, and ultimately interview the healthcare professionals using the composed questionnaire (See Appendix A for a copy of the proposed questionnaire to be administered). I hope to interview as many health care professionals as I can: doctors, nurses, CNAs, social workers, during my time at each institution.

I plan on arriving at each location at 8am and rounding with the physicians, observing their work with patients, and subsequently interviewing the health care professionals. I recognize that ideally, the subjects that I would interview for this project would be the patients themselves. However, after long consideration, I determined that the emotional toll that some of my questions may take on subjects—if those subjects were, in fact, the patients—would make this a difficult project to execute with approval by the Parisian health care administrators. Thus,

through interviews with the Palliative Care Team, I would be able to acquire important information in a direct way while maintaining patient well-being.

I plan on collecting subjects' work title, age, years of experience in Palliative Care, and years in health care in general. Although I also plan to ask subjects' names, all subjects will be assigned an identification number for the purposes of my data analysis so that subjects' anonymity and confidentiality will be preserved throughout this process. I plan on administering the questionnaire in paper form, while also recording the interview sessions on a digital recording device so that I may access and review the information acquired. The prompts for the conversation will be questions #4-9.

Proposed Timeline:

October 2013—Attend 2013 Clendening Fellows' Presentations
 November 29, 2013—Meet with Kim Connely and Irina Aris: Office of International Programs
 December 18, 2013—Meet with Dr. Hayley to discuss project
 December 19, 2013—Meet with Dr. Hayes to compose French email Palliative Clinics
 January 6, 2014—Attend Clendening Proposal Writing Workshop
 January 15, 2014—Shadow Dr. Landzaat on the Palliative Care Service at KU Hospital
 January 27, 2014—Meet with Dr. Landzaat to learn about the Palliative Services at KU Hospital
 March, 2014—submit project for IRB approval
 Present to May 24, 2014—Shadow at the KC Hospice and Palliative Care
 May 25, 2014—Leave Kansas City
 May 26, 2014—Arrive in Paris
 May 27-June 13, 2014—Interview and shadow/volunteer at Necker Enfants Malade Hospital
 June 16-June 20, 2014—Interview and shadow at University of Paris, Descartes, Sorbonnes
 June 23-July 4, 2014—Interview and shadow/volunteer at Cognac-Jay Hospital
 July 7-July 1, 2014—Interview and shadow at National Resource Center for Palliative Care
 July 14-July 18, 2014—Interview and shadow/volunteer at HAD Home Hospitalization
 July 20, 2014—Leave Paris
 July 21, 2014—Arrive in Kansas City
 July 22-July 25, 2014—Analyze data and complete project
 October 2014—Present research findings

Methods

Prior to leaving for this project in May, I plan on brushing up on my French-speaking skills by meeting with a fellow M1 classmate who is fluent in French and has agreed to help me. This will refresh my confidence so that I am more comfortable in the immersed-setting. Additionally, I recognize that there is an entire language of health care terms in French with which I am unfamiliar. I have explored many online resources and purchased several applications that are specific for medical French. I plan on reviewing French medical terms weekly and solidifying that part of my vocabulary prior to leaving in May.

Upon arrival in Paris, I plan on taking the train to the location of my family's apartment at 50 Boulevard du General Leclerc, 92200 Neuilly Sur Seine on the immediate outskirts of Western Paris. My room and board will be free, although food and transportation—both expensive in such a city—will be of substantial cost. During the work week, I plan on taking the subway to each location (about 3.5 Euros, or about \$5 per day) and eating on a budget.

As previously mentioned, upon arriving at the particular site for the week, I plan on shadowing the health care professionals—having been given previous permission to do so as seen in the correspondences in Appendix C. I will subsequently administer the questionnaire and record the interview session, with permission from the health care professional. Over time, I hope to be given the opportunity to conduct a medical interview and physical exam on patients under the supervision of the attending physician. This would immerse me in the French health care practices as nothing else could, and allow me to practice my clinical skills in a unique environment unlike any other.

Contacts:

Dr. Bruce E. Hayes

Dr. Deon Hayley

Dr. Lindy Landzaat

Pr Marcel Louis Viallard
Hôpital Universitaire Necker Enfants Malades
EA 4569, Université Paris Descartes, Sorbonne Paris Cité

Patricia Le Chêne
Hôpital Cognacq-Jay
Service de soins palliatifs

Dr Marie-Odile Frattini
Centre National de Ressources Soin Palliatif

Budget

- See Appendix E for Airline ticket cost confirmation

Item	Notes	Approximate Cost
Airplane ticket	Round trip, MCI and CDG	\$1,458
Food	55 days x \$20 per day	\$1,100
Transportation	39 workdays x \$5 per day	\$195
Laundry	3 times x \$10	\$30
Living Expenses	Staying with family in Paris	\$0
French Visa		\$82
Total		\$2,865
Clendening Summer Fellowship		-\$2,500
Left over		\$365
KUMC International Programs European Traveler's Scholarship	Discussed with Kim Connelly, will apply	-\$500

***I recognize that any cost beyond the \$2,500 is my responsibility and I have planned accordingly.**

Appendices

Appendix A: Questionnaire in English

1) The patient was happy to receive palliative care.

0	1	2	3	4	5
NA/Do not know	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

2) The patient had an accurate understanding of his or her illness/prognosis.

0	1	2	3	4	5
NA/Do not know	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

3) The patient was comfortable talking about death.

0	1	2	3	4	5
Not available/do not know	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

Qualitative Portion of Questionnaire:

- 4) Was the patient's experience a "typical" one?
- 5) What things were important to the patient?
- 6) How would you describe the patient's attitude or demeanor?
- 7) What patient qualities are important for that patient to have a positive end-of-life experience?
- 8) What qualities make it more likely that the patient will have a negative experience with end-of-life?
- 9) What factors determine whether or not a person fears death?
 - a. Work/Income?
 - b. Education?
 - c. Family/Friends?
 - d. Religion?
 - e. Hobbies/Interests?
 - f. Personality?

Appendix B: Questionnaire in French

1) Le patient était content de recevoir des soins palliatifs.

0	1	2	3	4	5
Je ne sais pas	En Total Désaccord	En Désaccord	Sans opinion	D'accord	Complètement D'accord

2) Le patient comprenait bien la maladie.

0	1	2	3	4	5
Je ne sais pas	En Total Désaccord	En Désaccord	Sans opinion	D'accord	Complètement D'accord

3) Le patient était à l'aise de parler au sujet de la mort.

0	1	2	3	4	5
Je ne sais pas	En Total Désaccord	En Désaccord	Sans opinion	D'accord	Complètement D'accord

4) Est-ce que l'expérience de ce patient était un cas typique ?

5) Quelles choses étaient principales au patient ?

6) Comment décrivez-vous l'attitude ou le comportement du patient ?

7) Quelles principales qualités est-ce qu'un patient doit avoir pour assurer des positifs soins de fin de vie?

8) Quelles principales qualités font le patient plus probable d'avoir une expérience négative avec les soins de fin de vie ?

9) Quels facteurs déterminent si le patient a peur de la mort ?

- a. Travail/Revenu ?
- b. L'éducation ?
- c. Famille/amis ?
- d. Religion ?
- e. Loisirs/intérêts ?
- f. Personnalité ?

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Learning How to 'Be' a Doctor: A Look at the Decline in Empathy and the Role of Medical Education in the Professionalization of Medical Students

Clendening Fellowship Proposal, 2014

Margaret Wilkes, University of Kansas School of Medicine

Introduction:

Many clinicians-in-training enter medical school with highly idealized visions of becoming both highly competent and highly caring physicians who strive to provide a superior level of care to their future patients. However, this idealism, while not necessarily lost, evolves throughout their training. Studies show an overall decline in empathy among medical students during their education.^{1,2,3} Empathy is cited as one of the most important core characteristics of the physician with correlations between higher empathy and increased patient satisfaction and compliance.^{3(p244)} The American Medical Association⁴ recognizes this decline in positive attitudes during training and regards empathy and professionalism as products of the learning environment. Their Initiative to Transform Medical Education published a 2010 report^{4 (p7)} that identifies a need for further exploration into the role of medical curriculums on professional learning objectives. What is it about the educational process and the culture of medicine that influences students' perceptions of patients, and even of themselves? With the support of the Clendening Fellowship, I aim to investigate the evolution of empathy at the University of Kansas School of Medicine (KUSOM) and to explore the development and role of both the formal and informal curricula in medical student socialization.

Background:

My interest in science and medicine has always been complemented by an equal, or even greater, interest in people and cultures. This led me to pursue a bachelor's degree in medical anthropology before I applied to medical school. For my senior capstone project at Case Western Reserve University, I did a general literature review on the professionalization of medical students. In this project I discussed aspects of medical education such as the gross cadaver lab, the subsequent construction of the patient, and the changing social boundaries students face conducting intimate patient interviews. An anthropological view on the professionalization of students is unique and important because of the discipline's focus on the navigation of the individual in a larger system or culture. Additionally, familiarity with anthropological data gathering methods such as participant observation, interviews, and focus groups is beneficial for developing answers to questions that my Clendening proposal asks. Exploring this topic of medical enculturation is fascinating and all the more relevant now that I myself am undergoing medical training. There are many changes that medical students undergo before they are considered or even feel like physicians. Education as an institution contributes more than just the biomedical knowledge needed to treat the human body. I am deeply interested in learning more about the intimate relationships between medical education and the development of the physician as a self and a professional, and my anthropological background has prepared me to further invest myself in such a project.

Description:

This summer, I would like to work with students and faculty at KUSOM to first gather a cross-sectional picture of trends in empathy among medical students through quantitative and qualitative means. Additionally, I hope to learn more about the development of medical curricula and use the data gathered from students to gauge the influence of various aspects of medical education on professional development.

The primary goals I would like to accomplish through the project are as follows:

- Develop a definition of empathy in the medical setting
- Gather and analyze statistical data on the status and evolution of empathy in students at KUSOM
- Obtain student narratives on empathy to augment objective data
- Critically explore the process of curriculum development and implementation at KUSOM and the roles of the formal and informal curriculum on professional development

First, I plan to conduct a preliminary literature review to garner a sense of the usage and meaning of empathy in the medical setting, in both the clinical and academic environments. After gaining a better understanding of empathy in practice, I will develop a definition to be used in my research for the following weeks. Once I have defined my research parameters, I will use aggregate data collected by KUSOM. KU administers the Jefferson Scale of Empathy for Medical Students at several points throughout students' education. This will give me a cross-sectional as well as longitudinal perspective of empathy differences among various classes. I will be working with Dean Bonaminio and Dr. Paolo to gain access to this information.

The heart of my project, however, is to gather qualitative narrative data that can be associated with and used to augment survey results. I plan to use e-mail and social media to recruit representative groups of 10-12 students per class, from incoming M1s to graduating M4s, and conduct focus group sessions. The incoming M1s, with no medical training, will be used as a baseline to measure differences in the other years. The goal of these sessions will be to facilitate a candid and confidential discussion among peers about their medical school experience. I plan to record these sessions and look for trends among dialogues to look for differences in responses among the classes and to see what students themselves cite as being the biggest influences on their self-perception of empathy and overall professionalization.

For the second part of my project, I would like to turn away from the students and look at KUSOM at an institutional level. I plan to look at the structure of KU's curriculum throughout all four years to see where and how empathy is taught or discussed. Additionally, I plan to speak with different faculty to look at the process of how changes in the curriculum are developed and implemented. Additionally, I would like to explore more about the differences between the formal and informal curriculums in medical education. Finally, I plan to compile all of my learnings and data from my project to critically analyze how students at KU are influenced by the curriculums. The following is a general timeline of how I plan to conduct my project.

Week 1: Conduct a literature review on empathy in medical students and medical curriculum

Week 2-5: Collect raw data through Jefferson survey results and focus groups. I will work around student schedules, such as Step 1 and the beginning of clinical rotations for incoming M3s.

Week 6: Meet with KUSOM faculty and staff to discuss curricular development at KU and specific efforts KU has taken to avoid erosion of empathy; gather data about the incidence and objectives of empathy teachings in KU's current curriculum

Weeks 7-8: Finish analyzing data and write report/prepare presentation

Methods:

Throughout the development of my projects, I have formed several relationships with KU faculty who will act as guides for my projects. Dr. Jana Zaudke from the Department of Family Medicine shares similar research interests in medical education and has agreed to serve as a mentor for my project. She will also work with me to perform a thematic analysis on the focus group transcripts. In the meantime, I will be observing the Major Society Professionalism Case Discussions for first and second year students in late February to begin field observations and develop topics and questions during later focus group sessions.

Additionally, Dr. Giulia Bonaminio in the Office of Medical Education has graciously agreed to act as a liaison between myself and the University in order to gain access to both past and present syllabi, learning objectives, and curricular structures, as well as to utilize systems such as JayDocs to document the distribution of empathy and professionalism throughout the

four-year curriculum. She has also volunteered to put me in direct contact with Dr. Bruce Newton at the University of Arkansas and Dr. Veloski at Jefferson Medical College, both of whom have spent years studying empathy in medical students and whose research is directly applicable to my exploration of empathy here at KU. Dr. Griebeling also agreed to talk with me this summer as I explore the role of KU's academic societies in students' medical education.

Budget:

The following is a tentative budget for my project. Any additional or unexpected costs above the total of the Clendening Fellowship, should I receive it, will be covered by my personal savings.

Thank you gifts for approximately 50 focus group volunteers	\$500
Rent/Utilities for June and July.....	\$1000
Groceries for 8 weeks.....	\$500
Expected Total.....	\$2000

The support of the Clendening Fellowship would be greatly appreciated in allowing me to further explore a topic that is of both academic and personal interest to me as I navigate through my own medical education and professionalization.

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