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Basic Science, Clinical & Translational Research

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Batten Disease Impact and Quality of Life in Unaffected Siblings

Introduction: The neuronal ceroid lipofuscinoses (NCLs; Batten Disease) are a group of rare, autosomal recessive lysosomal storage diseases, primarily of pediatric onset. Batten Disease is associated with an accumulation of lipopigments in neurons and other cells leading to progressive neurodegeneration and ultimately, death¹. Initial studies showed an impact on family functioning as behavior problems in the juvenile NCL form rose, but there is still much to be explored about the impact of Batten Disease on the unaffected siblings². Support studies identifying areas of need in care of the Batten patient have found that parents and siblings alike desire more support for the unaffected children³.

Objective: To quantitatively examine the association, if any, between knowledge of Batten Disease and quality of life in unaffected siblings and to quantitatively/qualitatively examine relationships among disease impact, quality of life, and disease knowledge in unaffected siblings.

Background: Healthy siblings have been an often overlooked family component in studies on chronic childhood illness and disability and pediatric cancer. Recurring themes in the existing literature show a gap in parental and medical knowledge in addressing the needs and issues of the unaffected siblings^{4, 5, 9}. Parents and siblings alike desire more information⁹. Studies on supportive interventions, such as group therapy or educational summer camps, for unaffected siblings have been found to positively impact sibling functioning in both chronic illness models (Spina Bifida, ADHD, CF, physical disability) and pediatric cancers⁶⁻⁹. Research evaluating sibling needs has yet to be conducted with unaffected siblings of Batten Disease patients.

Methods: Participants, ages 13 and older, were unaffected siblings who have lived with their sibling with Batten Disease at some point. Participants were recruited via mail or at the annual Batten Disease Support and Research Association (BDSRA) conference in Charlotte, NC. All participants completed 3 questionnaires that assessed knowledge of Batten Disease, impact of disease, and quality of life. The Teen and Adult Batten Disease Knowledge Survey has 14 or 15 true/false questions, respectively and knowledge is assessed in three areas: general Batten Disease knowledge, general genetics, and Batten Disease specific genetics. The Sibling Perception Questionnaire (SPQ)⁸ is a 29 item survey that assesses the participant's own perception of a sibling's illness (i.e., "*I feel my brother/sister with Batten Disease gets more attention from people than I do*"). Items are categorized into 5 domains—intrapersonal, interpersonal, communication, fear, and other, and are rated on a 5 point scale (1 = never, 5 = always). Higher scores on the SPQ are considered to reflected greater disease impact or disease burden overall and in the individual domains. Quality of life was evaluated using established and validated measures. Adults (ages 18+) completed the Quality of Life

Inventory¹⁰, which contains 32 questions on importance and satisfaction in 16 domains of daily life. Teens (ages 13-17) completed the PEDS QL Teen Report¹¹. The survey has 23 questions in 4 domains-physical function, emotions, social relationships, and school. For both quality of life surveys, higher scores indicate a greater quality of life. Analysis of data was completed using the statistical program, Statistica¹². A Spearman rank correlation (for non-parametric data) was used to evaluate all correlations between measures and statistical significance was set for p-value < 0.05.

Results: All participants were ultimately recruited and enrolled in person at the BDSRA meeting. Out of a total of 15 participants, 10 were female and 5 were male with a mean age of 21.07 years (s.d. 5.28 years). There was a statistically significant difference in mean age between males and females (mean female age = 17.90 years, s.d. = 3.18 years; mean male age = 27.40 years, s.d = 4.51 years). There were no other statistically significant differences between males and females. Spearman rank correlations were significant for total SPQ score and knowledge of Batten Disease genetics ($r = -0.5356$, $p = 0.0396$); fear of disease and overall knowledge of Batten disease ($r = -0.6768$, $p = 0.0056$). Correlations between all other proposed variables were found to be non significant and non meaningful. Post-hoc analysis in a subset of participants of siblings with the juvenile variant of Batten Disease (JNCL; $N = 11$) revealed a significant correlation between the number of BDSRA meetings attended and total SPQ score ($r = 0.6879$, $p = 0.0193$).

Conclusion: The aim of the study was to explore the relationships among disease impact, quality of life, and knowledge of Batten Disease in unaffected siblings. While we did not observe a significant association between overall quality of life and knowledge of Batten Disease, our results show relationships between knowledge and aspects of disease impact. There was a modest, but significant relationship observed between disease impact and knowledge of the genetics of Batten Disease. The study also showed a statistically meaningful association between fear of Batten Disease and how much they knew about the disease. One curious finding in the subset of siblings of JNCL patients was the positive association between number of BDSRA meetings attended and the total disease impact. It is unclear whether this is because of more years spent with the affected child or due to some other confounder. Unfortunately, we had a very small sample size and a possibly biased population and these factors may contribute to our findings. Our results suggest opportunity for further research to better understand the nature of the relationship between fear of Batten Disease and knowledge. Research evaluating supportive interventions and their effects on disease impact and knowledge may prove more helpful in elucidating causal relationships and areas for improvement in sibling support.

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Basic Science, Clinical & Translational Research

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Comparing Genetic Expression of α 1A-Adrenergic Receptors in Hippocampus and Prefrontal Cortex of AQP4KO and WT mice

Introduction: Norepinephrine is a catecholamine that perhaps is best known for mediating the fight-or-flight response of the sympathetic nervous system. Other than being an important neurotransmitter in the body's stress response, norepinephrine also has a central role in the brain with respect to multiple higher level functions. Noradrenergic neurons in the brain form tracts that originate in the locus coeruleus and affect various areas in the brain that control many cognitive functions. This includes modulating mood, learning, and memory. It mediates these effects by selectively binding to and activating a family of proteins known as adrenergic receptors (AR), which have been subtyped according to their structure, physiologic characteristics, and pharmacologic properties into α and β groups. The α and β groups are divided even further and classified as α 1, α 2, etc. α 1A-adrenergic receptors have been shown to be involved in higher cognitive function with respect to attention, memory, and learning and they were the subject of this research.

Objective: To assess and compare the level of gene expression of α 1A-adrenergic receptor between prefrontal cortex and hippocampus in WT and AQP4KO mouse brain using QT-PCR.

Background: It has been demonstrated that long term stimulation of α 1A-adrenergic receptors increases neurogenesis (Gupta et al, 2009), cognitive function, longevity, and improves mood (Doze et al., 2011). There has also been evidence that newly generated neurons contribute to learning and memory, which are functions that are particularly dependent on the hippocampus (Deng et al 2010). Furthermore, the hippocampus and cortex of mouse brain have been shown to have relatively high density of α 1A-adrenergic receptor (Jones et al 1986). The fact that α 1A-AR was found to be expressed in astrocytic cell culture (Hertz et al., 2010) provides further evidence of their important role in brain biology. Behavioral studies conducted in Vates lab have shown AQP4KO mice showed no improvement in novel object recognition testing after being administered atipamezole, an α 2AR antagonist. Research in Vates lab has also shown AQP4KO artery and penetrating arteriole diameters were not affected when mice were administered atipamezole. Furthermore, norepinephrine levels have been shown to be higher in AQP4KO prefrontal cortex (Fan et al., 2005), which could indicate there is a lack of adequate receptor density for norepinephrine to bind. We hypothesize that AQP4KO mice underexpress α 1A-AR in areas of the brain that are important for tasks in attention, memory, and learning, notably the hippocampus and prefrontal cortex.

Methods: Brain tissue was surgically harvested from 10-12 week old AQP4KO/B6C57 mice (The Jackson Laboratory, Bar Harbor, ME). Each group consisted of 8 mice. The mice were deeply anesthetized with isoflurane and immediately decapitated. The brain was immediately removed to ice

cold aCSF. While submerged, the prefrontal cortex and hippocampus were dissected free of white matter, transferred to RNase free tubes, and flash frozen with ethanol and dry ice. The Trizol Reagent protocol for RNA isolation was used (Life Technologies). Reverse transcription and QT-PCR was performed on isolated RNA using Taqman Universal PCR Master Mix protocol (Applied Biosystems). Data was obtained and analyzed using ABI Prism 7000 Sequence Detection System, with GAPDH used as the internal control gene.

Results/Conclusion: Expression of $\alpha_{1A}AR$ was unregulated 2.22x in AQP4 mice hippocampus as compared to WT mice hippocampus. There was no difference in expression of the $\alpha_{1A}AR$ gene between the different mouse lines in tissue harvested from the prefrontal cortex. According to this data, AQP4 mice theoretically should perform better as compared to WT mice in behavior-testing tasks, such as novel object recognition. However, due to the small experimental groups and lack of a difference in prefrontal cortex gene expression, it is difficult to characterize the relationship between $\alpha_{1A}AR$ density and behavior data. Furthermore, other adrenergic receptor subtypes could be of more importance in learning and forming memories. Further work will be directed towards identifying other adrenergic receptor subtypes and their level of expression in these brain regions between mouse lines.

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Basic Science, Clinical & Translational Research

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tRNA Splicing and Pontocerebellar Hypoplasia

Introduction: In the human genome there are 506 genes encoding for tRNA molecules, of those, 32 contain an intron that must be spliced for proper function. The splicing of tRNA occurs by a distinct mechanism from the splicing of mRNA. Correct tRNA splicing is a process vital to proper neural development as evidenced by patients with pontocerebellar hypoplasia who have been identified to have mutations in *tRNA splicing endonuclease (TSEN)* family genes. These children exhibit severe hypoplasia of the pons and cerebellum and rarely survive into their teenage years. The four-member *TSEN* family forms a heterotetramer that is necessary for tRNA splicing. Why mutations in *TSEN* family genes cause a predominately neurological phenotype is unclear.

Objective: To determine if the splicing of intron-containing tRNA genes or expression of genes involved in tRNA splicing in phenotypically normal mice is regulated in a temporal or organ-specific manner.

Methods: Total RNA was isolated from total brain, liver, thymus, heart, spleen, gastrocnemius, and kidney of postnatal day 0 (P0), P10, and P30 C57BL/6NJ mice. Radiolabeled DNA probes were used for Northern blot analysis of tRNA levels in various tissues at various time points. Oligonucleotide probes were designed for RT-PCR and RT-qPCR were used to analyze the transcript levels of *Tsen* family genes in the same tissues.

Results: We show that immature tRNA accumulates at high levels in the brain, spleen, and thymus compared to other organs tested. Further we show that *Tsen54* and *Tsen2* have significantly diminished expression in the brain of phenotypically normal P30 mice.

Conclusions: These results suggest that tRNA splicing undergoes unique regulation in the brain and this is a possible contributing mechanism to the organ specific pathology found in pontocerebellar hypoplasia. The apparent lack of two of the four *Tsen* subunits at P30 even in the clear presence of functional tRNA splicing suggests that an as yet undiscovered, alternative tRNA splicing mechanism exists in mice. It also suggests that *TSEN54*, the most commonly mutated subunit in pontocerebellar hypoplasia, may not be necessary beyond the neonatal period which would make it an ideal target for intrauterine gene therapy. Further studies regarding the effect of conditional knockouts in mice for the *Tsen* genes are warranted and could provide deeper insight into the pathogenic potential of these genes.

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Basic Science, Clinical & Translational Research

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In Search of Compassion: A Preliminary Taxonomy of Compassionate Behaviors of Physicians

Introduction: For many ages, compassion has been extolled as a virtue in the physician-patient relationship, especially in situations in which patient suffering is most evident. However, there are few studies that systematically document the behavioral features of physician compassion and ways in which physicians communicate compassion to patients.¹⁻³

Objective: To describe a taxonomy of compassionate actions expressed by physicians that can be discerned by an outside observer.

Background: Compassion begins with recognition of a patient's suffering, accompanied by an internal response to the suffering (often called emotional resonance) and a desire to relieve the patient's suffering through presence, word, and action.⁴⁻⁷ In contrast to empathy (another quality encouraged in clinical care that is primarily a cognitive skill involving understanding of patients' concerns^{5,8}), compassion emphasizes emotional resonance – active imagination of the sufferer's condition, concern for his or her good, and sense of sharing his or her distress.⁴ Compassion is also distinguished from other prosocial behaviors in that compassion compels the individual to act to alleviate suffering,⁷ even when such relief is only partially successful.⁴ In the setting of life-threatening illness such as advanced cancer, suffering often is apparent and patients provide both direct and indirect cues to their distress; however, compassion often appears to be lacking.^{9,10}

Methods: This summer project was embedded within a larger project, the Advanced Cancer Communication Study. At the time of analysis, oncologists (n=18) and their patients with terminal cancer (n=49) were recruited in the greater Rochester area. They agreed to be surveyed and have office visits audio-recorded for baseline assessments of communication skills prior to a large randomized trial. My summer work began with developing a theoretical model of compassion using sources from the social sciences,^{11,12} nursing,^{7,13} fiction,^{14,15} religion,¹⁶ bioethics,^{5,17,18} and general health professions.¹⁹ This model was subsequently used as a sensitizing framework to analyze the audio recordings qualitatively. Data were analyzed and coded for displays of compassion, themes were developed, and exemplars were selected for reporting.

Results: Our sensitizing framework was oriented around three elements of compassion: recognition, emotional resonance, and desire for action. Statements of compassion, which were found in approximately a third of the 38 audio-recorded conversations selected for analysis, included direct statements, paralinguistic expressions, and performative comments. Compassion frequently unfolded over the course of a conversation rather than appearing as a single discrete event.

Conclusion: Several observable markers of compassion in clinical encounters were found and organized into a taxonomy of behavioral responses to patient suffering. While not all components of

compassion, particularly emotional resonance, may be expressed verbally by the physician, these elements yet may be perceived by the patient through nonverbal elements (e.g. silence) and behaviors. Further research will be needed to validate and add nuances to this preliminary taxonomy so that this information can inform education and training interventions intended to facilitate compassion in physician-patient interactions.

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Basic Science, Clinical & Translational Research

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Identification of chromosomal aberration variations between asbestos-induced and radiation-induced peritoneal malignant mesothelioma

Objective: To study the pathogenesis of asbestos versus radiation attributed peritoneal mesothelioma by comparing chromosomal aberrations found in tumor samples from patients with disease attributed to radiation or asbestos exposure.

Background: Malignant mesothelioma is a rare cancer that is diagnosed in 2,000 new patients and responsible for approximately 3,000 deaths each year in the US. (Carbone, Ly) It is an aggressive tumor that arises from mesothelial cells on the serosal cavities of the body. Pleural mesothelioma is the most common form, accounting for roughly 60-70% of malignant mesothelioma cases while peritoneal mesothelioma accounts for the majority of the remaining 30%. (Yang) Other sites that can be affected by mesothelioma include the pericardium and the tunica vaginalis of the testes and ovaries. (Musti, Kettunen)

Pleural mesothelioma is commonly associated with asbestos, with an attribution of 70%. Peritoneal malignant mesothelioma (PMM), in contrast, has a weaker attribution to asbestos of 30%. (Sebbag, Sugarbaker) Other recognized causal factors for malignant mesothelioma include medical radiation therapy. Studies have shown a statistically significant increase in the number of mesothelioma cases following radiation therapy for breast cancer, testicular cancer, Hodgkin's lymphoma, and non Hodgkin's lymphoma. (Goodman) The presentation of the disease appears to be similar regardless of causation, but the molecular pathogenesis of asbestos versus radiation attributed peritoneal mesothelioma is unknown.

Methods: We identified 37 cases of snap frozen epithelioid PMM tissue from the Columbia University Cancer Center Tissue Bank. Manual microscope guided needle dissection of cryostat frozen sections was performed obtaining a minimum of 500ng of tumoral DNA. DNA was prepared as per Affymetrix protocol for digestion, ligation, amplification, purification and labeling with standard quality metrics for fragment size prior to hybridization on Affymetrix SNP 6.0 array. Array results were analyzed using Nexus Copy Number 6.0 software (Biodiscovery, Hawthorne CA).

Results: Ten of the 37 PMM cases were attributed to asbestos exposure and seven to radiation exposure. In asbestos attributed cases, patient age ranged from 45-78 (8 men and 2 women) and in the radiation attributed cases, patient age ranged from 49-88 (6 men and 1 woman).

Chromosomal aberrations were compared statistically between the asbestos and radiation groups and one prominent region was evidenced in chromosome 14q where significant loss was shown in asbestos cases, but not radiation cases as highlighted in Figure 1.

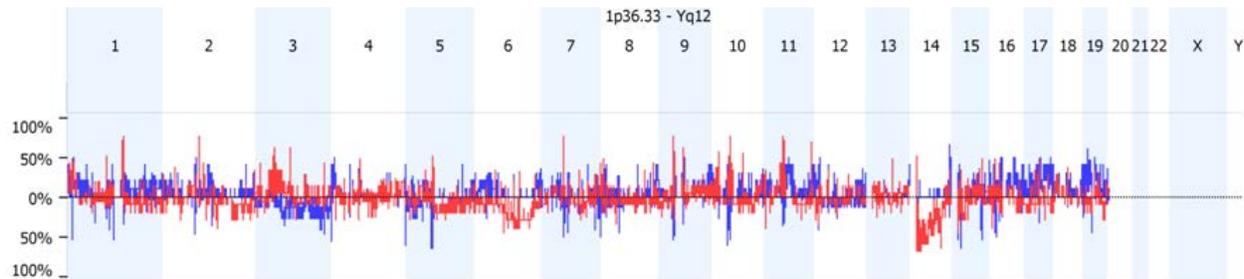


Figure 1. Frequency of chromosome loss and gain in asbestos (red) versus radiation (blue) induced PMM

When chromosome 14q was further analyzed, loss of 14q11.2-14q13.3 and 14q21.1-23.2 was seen in up to 7 of 10 cases (70%) of asbestos attributed mesothelioma and in 0 of 7 (0%) of the radiation attributed cases.

Conclusion: Copy number analysis using SNP mapping arrays revealed losses at 14q11.2-13.3 and 14q21.1-23.2 in up to 70% of PMM patients after asbestos exposure compared to no deletion in PMM patients after radiation exposure. While the significance of this loss is unknown, identification in asbestos induced PMM in contrast to radiation attributed PMM suggests a distinct molecular pathway for asbestos induced versus radiation induced epithelioid PMM.

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Basic Science, Clinical & Translational Research

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Insulin effects on CSF and fluid bulk flow in the brain

Introduction: Idiopathic intracranial hypertension (IIH) is a significant cause of headache¹. Pressure on the optic nerve can lead to blindness, and some patients may need shunting to reduce their intracranial pressure (ICP). Risk factors for IIH include obesity, cyclosporine/minocycline treatment, polycystic ovarian syndrome, hyperinsulinemia/metabolic syndrome, and vitamin A toxicity²⁻⁴. These risk factors either cause decreased CSF resorption because of increased venous pressure, or may increase CSF production at the choroid plexus, but the true pathophysiology of IIH remains incompletely understood.

Objective: Our goals were to develop a better understanding of CSF production, elucidate the effects of insulin on CSF production, and develop an animal model of idiopathic intracranial hypertension. Our secondary goal was to develop basic science evidence to support novel translational medical therapies.

Background: CSF is produced predominantly at the choroid plexus (CP) in which cells produce an osmotic gradient through activity of the Na/K ATPase pump, allowing osmotic gradients to draw water into the ventricles⁵⁻⁹. Receptors for insulin and IGF-1 are highly expressed in the murine choroid plexus transcriptome, and are believed to play an exquisite role in the regulation of Na/K ATPase activity. Despite this finding, the effects of insulin on CSF production remain largely unknown, even though many of the predisposing factors that are associated with IIH also cause insulin resistance or hypersecretion.

Methods: *In vivo* CSF and ECF inflow and outflow measurements utilizing low molecular weight fluorescent tracer techniques developed in the Nedergaard lab were obtained from lightly anesthetized, C57BL/6J mice.

Results: Insulin exhibited what appeared to be a mild stimulatory effect on CSF production and flow. This effect was inconsistent, partly due to previously described interactions with ketamine-based anesthetics.

Conclusion: Insulin's effects on CSF production and flow remains to be a controversial topic in modern neurological research. Our limited data serves to support the theory that insulin may play a role in CSF production by acting on choroid plexus cell ionic pumps. Without conclusive data, however, the true effects of insulin on CSF production cannot be characterized. Anesthetics that do not alter normal neural insulin and IGF-1 responses must be obtained and used in order to obtain reliable data. Alternatively, experimentation on non-anesthetized, awake mice would allow one to

bypass the hurdles of working with homeostatic-altering anesthetics such as Ketamine, Isoflurane, and Urethane, all which have detrimental effects on insulin activity in the neurological system.

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Basic Science, Clinical & Translational Research

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Development of a Novel *In Vitro* Clot Degradation Assay

Introduction: In the study of hemostasis and various related pathological states, it has become essential to be able to measure fibrinolytic reactivity. To date, several tests exist to both quantitatively and qualitatively examine the presence of plasminogen activators and plasmin in samples. However, no assay exists to measure the functional aspect of plasmin, which would provide a better understanding of clot breakdown or fibrinolytic reactivity. Our research has focused on developing a reliable and reproducible assay to detect the activity levels of plasminogen activators (PA) and plasminogen activator inhibitor-1 (PAI-1) in cell culture samples.

Objective: The aim of this study was to develop an assay to measure the PA and PAI-1 activity, as defined by fibrinolytic reactivity, in cell culture samples.

Background: The main step in the formation of a clot is the conversion of fibrinogen to fibrin, which is catalyzed by the enzyme thrombin. It is also essential to have a mechanism in place to break down clots. Tissue plasminogen activator (tPa) and urokinase plasminogen activator (uPa) are two enzymes that convert plasminogen to its activated form, plasmin. *This activated plasmin is responsible for the enzymatic degradation of the fibrin clot, a process known as fibrinolysis.* The amount of plasmin generated is determined by the concentration of plasminogen activators and their inhibitor, plasminogen activator inhibitor-1 (PAI-1). A greater understanding of the process of clot formation and fibrinolysis has become an important area of research in order to find better ways to treat deep vein thrombi (DVTs) and their sequelae, including pulmonary emboli.

Methods: To form clots, thrombin was added to fibrinogen and incubated at 37°C for 24 hours. The samples were then centrifuged to form a pelleted, compact clot that was dried and weighed. The clot was then coincubated with plasminogen and uPA or unknown test samples, and fibrinolytic reactivity was measured as percent clot degradation as determined by the decrease in clot weight after 24 hours. Appropriate concentrations of thrombin and plasminogen were determined based on dose response curves conducted as part of the assay development.

Results: After completing fibrinogen and thrombin dose responses to find the appropriate concentrations of each to use for clot formation, a uPa dose response experiment was conducted to

demonstrate that increasing concentrations of uPa would correlate to increasing percentages of clot degradation. Each ten-fold increase in uPa concentration, from 150 fM to 15 nM, resulted in an average of 13.6% clot degradation.

To determine the validity of this assay using cell culture samples, endothelial cells from two different venous beds were used. Human iliac vein endothelial cells (HIVEC), a lower extremity vascular bed that is susceptible to clot formation, and human pulmonary artery endothelial cells (HPAEC), from the pulmonary circulation, were cultured in the absence or presence of TNF α (1 μ L/mL media) for 24 hours. Cell extracts and conditioned media were collected and incubated with clots at 37°C for 24 hours, to examine intracellular and secreted fibrinolytic reactivity, respectively. Incubation with TNF α -stimulated HIVEC cell extracts caused a 41% decrease in clot weight. In contrast, there was no clot degradation in the presence of TNF α -stimulated HPAEC. Interestingly, while the conditioned media samples from TNF α -treated HIVEC did not alter clot weight after 24 hours, there was a 20% decrease in clot size in the presence of media from the TNF α -stimulated HPAEC.

Conclusion: This study demonstrates the development of a novel and reproducible methodology to examine fibrinolytic reactivity in cell culture samples. Furthermore, our results demonstrate that endothelial cells from the pulmonary venous circulation exhibit greater ability to extrinsically degrade fibrin clots when compared to endothelial cells from a lower extremity deep venous bed. This increase in secreted fibrinolytic reactivity of pulmonary artery endothelial cells when compared to iliac vein endothelial cells may explain, in part, why more clots are found in the deep veins and not the pulmonary vasculature.

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Basic Science, Clinical & Translational Research

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Exercise-Induced Bronchoconstriction (EIB) In Atopic And Nonatopic Recreational Touring Bicyclists On A Ride Across America

Introduction: Exercise-induced bronchoconstriction (EIB) is characterized by acute narrowing of the airways during and following exercise.¹ While EIB has a 10% prevalence in the general population, it is significantly increased in endurance athletes. EIB has been reported to be as high as 50% in olympic cyclists.² This increase in prevalence is unlikely to be due to self-selection by cyclists, and it is therefore plausible that some link exists between cycling and the development or activation of EIB.

Objective: The purpose of this study is to determine if recreational cyclists participating in the Big Ride Across America, a 48 day charity bicycle ride that covers 3,300 miles from Seattle, WA to Washington, DC, experience a change in lung function over the course of the ride. Secondary analysis will compare lung function changes in atopic riders to nonatopic riders.

Background: Exercise-induced bronchoconstriction (EIB) is an inflammatory process in the airways that involves an increase in eosinophilic mediators.^{1,3,4} While the pathogenesis is not clearly understood, EIB is characterized by a transient constriction of the airways which reduces expiratory capacity following exercise. The condition is reversible spontaneously after 60-90 minutes or preventable with the use of β_2 agonists. The estimated prevalence of EIB in the general population ranges from 8 to 14 percent.^{3,6} In elite endurance athletes, however, the prevalence is significantly increased.^{2,5} Cyclists in particular have a high prevalence of EIB. Symptoms vary and can include shortness of breath, wheezing, chest tightness and cough.⁴ An exercise challenge is the most direct way to establish a diagnosis of EIB.⁷ Six to eight minutes of vigorous exercise are followed by measurement of forced expiratory volume in one second (FEV1). FEV1 is measured before, at 5, 10, and 15 minutes following exercise. A decrease in FEV1 of 10 percent or more is considered a positive screen. A 15 percent decrease is diagnostic of EIB.

Methods: Pre-ride Asthma Symptom and Cycling History Questionnaires were completed by participants to determine health history and to distinguish atopic individuals from nonatopic individuals. Those with 3 or more allergy and asthma symptoms or a previous diagnosis of asthma were placed into the atopic category. Exclusion criteria included age less than 18 and greater than 70 years old and/or previous participation in a professional sport at a national or international level. During the course of the seven week study participants averaged 85 miles of riding a day, with a range from 59 to 112 miles. Riding commenced at daybreak and lasted from 8 to 12 hours, depending on distance, weather, and road conditions.

Monitoring of lung function was achieved by two methods. First, peak flow meters were used to monitor changes between morning and evening baseline lung function. Each morning (before riding) and each evening (before bed) participants recorded peak flow measurements.

The second phase of monitoring involved weekly spirometry tests following an exercise challenge. Participants were split into 5 groups based upon pace and underwent a modified exercise challenge test, with each group being tested on a separate day of the week. For each group, the first 20 miles of the scheduled ride served as the exercise challenge stimulus. Spirometry testing was performed upon arrival at the first rest stop. Weather conditions were recorded.

Results and Conclusion: Data collection is complete, but statistical analysis remains in process at the time of abstract publication.

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Basic Science, Clinical & Translational Research

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Vestibular After Effects in Yaw Rotation

Introduction and Background: Known as the “waterfall illusion,” motion after effect (MAE) is a highly studied visual phenomenon. Many scientists and philosophers have reported on this effect, but it was not until 1834 that Dr. Robert Addams described MAE as it is defined today. Addams noticed that when he shifted his visual field from a constant-moving waterfall to the stationary rocks nearby, it appeared as if they were moving upward (1). While vision is the most investigated form of MAE, similar effects were seen in sound intensity (7), voice perception (4) and proprioception (8). Their findings all suggest a universal theme of reversed perception of subsequent stimuli in comparison to the initial exposure.

Vestibular after effects (VAE) are only recently studied, and most studies to date have focused on eye movement. Most notably, the vestibular system controls the vestibulo-ocular reflex (VOR), which stabilizes visual images on the retina during head movement. It accomplishes this through quick neuronal impulses, which innervate the extra-ocular muscles causing a compensatory eye movement in the opposite direction. During long rotations at a constant velocity, the vestibular stimulus decays. However, a neuronal mechanism exists to prolong the VOR, a condition known as velocity storage (5). A consequence of this is that the eye movements attributed to the vestibulo-ocular reflex will persist in the absence of vestibular stimulation (6). Recent data suggests that rotation perception may be linked to this velocity storage after a sudden stop (3) but the perception is in the same direction as the stimulus. Therefore, this velocity storage effect implies that after effects for rotation perception may be different than those described for other sensory systems.

Objective: The goal of this study is to determine whether or not subjects perceive a vestibular after effect subsequent to yaw rotation. Investigating a possible vestibular after effect related to rotation and reconciling this with velocity storage may provide a valuable insight into how motion is perceived.

Methods: A total of 10 subjects were placed in a seated racing seat inside a 6-degree-of-freedom motion platform (Moog, East Aurora, NY, model 6DOF2000E) with proper harnessing and a helmet. They were given a three-button control box to record their perceived direction of movement, with the middle button initiating the stimulus. Subjects were informed that during each trial they would be rotating either left or right.

The first trial was a single interval of motion with no secondary stimulus. Its stimulus pattern was the intertwining of two staircases, with a maximum stimulus of 12 cm of motion during 1.0 s.

The second trial tested after effects using an adapting stimulus (first interval) followed by a test stimulus (second interval). The first interval remained constant at 12 cm over 1.0 s. In between the intervals was an inter-stimulus interval (ISI) where no motion occurred. Each trial was limited to a single ISI of 0.5, 1.0, 1.5, or 3.0 s. After the ISI, a test stimulus was administered in the same fashion as the first trial. The test stimulus was also an intertwining of two staircases with a maximum movement of 5 cm in either direction. The length of each test stimulus was constant at 1.0 s.

The subjects were asked to stare at a focal point located directly in front of them at eye level during the protocol. The protocol was then repeated without a focal point. Both sequences of trials were performed in the dark with white noise to eliminate outside stimuli. An eye-tracking camera was placed just below the focal point and recorded eye movements, via pupil location, for each subject.

Each subject's data was plotted using a Gaussian function and resampled in order to fit 95% confidence intervals of the mean. A sigma value was also determined. In the test stimulus phase, the overlapping data for left and right yaw rotation was used to calculate a p-value and quantify an after-effect.

Results: With the focal point on, eight of 10 subjects showed a significant after effect ($p < 0.05$) at an ISI of 0.5 s. Seven of 10 showed an effect ($p < 0.05$) at 1.0 s, five of 10 at an ISI of 1.5s and two of 10 at an ISI of 3.0 s all with the focal point on. Average sigma values decreased as ISI increased. Testing with the focal point off showed that five of 10 subjects experienced a significant after effect ($p < 0.05$) at an ISI of 0.5 s. Four of 10 subjects had an after effect with the focal point off at an ISI of 1.0 s, while three of 10 subjects and two of 10 subjects experienced an effect with the focal point off at 1.5 s and 3.0 s respectively. Sigma values were higher with the focal point off when compared to the values recorded with the focal point on.

Conclusion: There appears to be a strong vestibular after-effect present in a majority of subjects during yaw rotation. As seen with the other aforementioned forms of stimuli, the effect is perceived in the opposite direction with a marked decay over increasing ISI. Early analysis of the eye data does not provide significant insight about vestibular after effects in relation to vestibulo-ocular reflex or velocity storage. However, it is hypothesized that velocity storage only occurs during long duration stimuli, which does not fall within the scope of this study.

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Basic Science, Clinical & Translational Research

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Association between Obesity during Pregnancy and the Adequacy of Prenatal Care

Introduction: In the United States, 1-in-4 women are obese (body mass index (BMI) >30).¹ Although obese populations utilize health care at increased rates and have higher health care costs than non-obese patients, the adequacy of prenatal care in this population is not well established and assumed to be suboptimal. ^{2,3}

Objective: We aimed to evaluate the adequacy of prenatal care among obese women.

Background: Previous research has demonstrated that obese women utilized health care during pregnancy at much higher rates than their non-obese counterparts.² In particular, even without high-risk pregnancies, obese women require a greater number of prenatal visits.²

Methods: We utilized a Strong Memorial Hospital database including 7091 deliveries with pre-pregnancy BMI \geq 18.5 from 1/09 through 12/11. Subjects were categorized as normal weight 18.5-24.9 kg/m², overweight 25-29.9 kg/m², and obese >30 kg/m² (class I-II-III). Adequacy of prenatal care (PNC) was evaluated using the Kotelchuck Index (KI), corrected for gestational age at delivery.⁴ Adequate care was defined as KI “adequate” or “adequate plus,” and non-adequate as “intermediate” or “inadequate.” Chi-square and logistic regression were used for comparisons.

Results: KI categorization was similar for normal and overweight women, and between classes of obesity, thus groups were combined into non-obese and obese. When compared to non-obese women, obese women were more likely to have adequate PNC (68.7% vs 74.1%; OR 1.30, 95%CI 1.15-1.47). After adjusting for age, race, education, diabetes, hypertension, and practice type, obesity remained a significant predictor of adequate prenatal care (OR 1.29, 95%CI 1.14-1.46). While age and hypertension were not significant independent predictors of adequate PNC, college education, Caucasian, diabetes, and resident or MFM care had positive associations.

Conclusion: Maternal obesity is associated with increased adequacy of prenatal care. Although some comorbidities associated with obesity increase utilization of prenatal services, this did not explain the improvement in PNC adequacy associated with obesity.

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Basic Science, Clinical & Translational Research

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Injury Patterns and Healthcare Utilization among Rock Climbers in North America

Introduction and Background: Rock climbing was once considered an “extreme” sport, practiced only by those predisposed to take risks. That is no longer the case. It is rapidly becoming the favored form of exercise for many individuals. The Outdoor Industry Association estimates that at least 6 million people have participated in rock climbing and that 1.3 million people climb 10 or more times per year⁶. Despite its popularity, many consider it to be a risky sport. Most research has found injury rates between 30%-50% among study participants^{1,3}. In a larger web-based study of 1,887 participants, 82.1% reported at least one injury².

The current research conducted on injuries among climbers shows dichotomized results. Research that defines an injury as withdrawal from participating in rock climbing showed that the most common mechanism of injury is caused by overuse or a single strenuous move. These types of injuries occur predominantly to the upper extremity, most notably the fingers, shoulder and elbow^{2,3}. Studies which only include injuries that were examined by a health care professional show that falls are the predominant mechanism of injury. Fractures, sprains and lacerations were the most common type found in these studies. The lower extremity was the most frequently injured body part, particularly fractures of the ankle or foot^{4,5}. In these studies the criteria for inclusion is stricter and thus misses many of the more common injuries.

Objective: There are two main objectives to this research:

- To determine if rock climbers will choose to seek medical care predominantly for acute trauma rather than overuse injuries.
- To describe patterns of injury with respect to many variables involved in rock climbing.

Methods: A survey was designed to obtain information about rock climber’s injuries. After approval by the University of Rochester Institutional Review Board the survey was piloted in a group of 20 individuals and was modified according to feedback. Surveys were distributed to climbers in person along with a recruitment letter at rock climbing destinations throughout North America. Distribution sites included, Bishop (CA), Yosemite National Park (CA), Smith Rock State Park (OR), Leavenworth (WA), and Squamish (Canada, BC). The data was coded and entered into excel. Data from surveys with missing responses was included in the analysis. Injuries were categorized as being caused by an acute event or overuse. Injuries were then grouped as examined by a physician or not. A chi square test was performed to determine statistically different types of injuries.

Results: One hundred and four individuals were approached to fill out the survey and 102 completed it. The average age of the participants was 28 years old. They rock climbed an average of three days

a week, 39 weeks a year, for 8 years. The sample was composed of 75% males and 25% females. The performance level of participants as measured by the Yosemite Decimal System ranged from 5.7 (beginner) to 5.14a (professional). The average grade climbed after repeated attempts (redpoint) and first try (onsight/flash) was 5.11c and 5.12a, respectively. This data indicates the survey population is composed of primarily advanced climbers.

One or more injuries were reported by 70.5% of individuals, totaling 108 injuries. The majority of these were finger injuries (34.3%), followed by the shoulder (13.8%) and elbow (13.0%). By far the most common type of injury was a strain (54%), second was joint pain (16%) and third was sprains (13%). Of the injuries, 49% were caused by an acute event, 36% were caused by overuse, and 15% did not provide information to allow an accurate classification. A physician examined 31% of the injuries. The majority of injuries examined by a healthcare provider were caused by an acute event (75%), whereas those not examined were caused equally by acute events (48%) and overuse (52%), a result that reached statistical significance ($p < 0.05$).

Conclusion: This study highlights how the injuries seen by doctors are different from those that are not. The injuries examined by a physician are predominantly caused by acute events while those that are not seen by a physician are caused equally by acute events and overuse. Research that uses only injuries that are examined by health care professionals may be missing up to 70% of the injuries that are experienced by rock climbers. For this reason, research using hospital records is limited at best and should only be done for well defined specific reasons. When a patient presents to a doctor's office with a climbing injury, it is likely they have experienced previous injuries that were not seen by a physician. Some of these injuries may have never healed completely. This situation provides an opportunity for the doctor to explore the patient's prior injuries as well as offer counseling focused on recovery techniques for strains, sprains, and joint pain.

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Basic Science, Clinical & Translational Research

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Hypogastric artery coiling predicts persistent or new type 2 endoleak after EVAR

Objective: Type 2 endoleaks are the most common complication of EVAR but their clinical significance remains controversial. Our objective was to determine risk factors of developing type 2 endoleaks and their association with adverse outcomes in the hope of informing reintervention strategies.

Methods: We performed a retrospective cohort study using the Vascular Study Group of New England AAA database. Patients were subdivided into 2 groups: 1) those with no endoleak at any time or those with a transient type 2 endoleak (endoleak at completion of case but lasting <6 months postoperatively and 2) persistent type 2 endoleak (endoleak at completion of case lasting >6 months post-operatively) or new type 2 endoleak (no endoleak at completion of case but with subsequent development). Patients with other endoleak types were excluded. Bivariate and multivariable analyses were used to evaluate predictors of persistent or new type 2 endoleaks. Kaplan-Meier survival analysis and Cox regression were used to evaluate predictors of reintervention and survival.

Results: Of 2757 patients who underwent EVAR, 1349 patients were in group 1 (80% men, 1023 no leak, 290 transient leak) and 245 patients in group 2 (78% men, 66 persistent leak, 175 new leak). Patients in group 2 were older (mean age 75 vs. 73 years, $P<.001$), less likely to have COPD (27% vs. 37%, $P=.004$), and fewer were on aspirin preoperatively (65% vs. 72%, $P=.012$). Having one or both hypogastric arteries coiled was associated with a higher rate of persistent/new leak (unilateral: 5.3 vs. 3.7%, bilateral: 1.9 vs. 0.3%, $P=.004$). Additionally, twice as many patients in group 2 underwent graft extension (14% vs. 7%, $P=.003$). In multivariable analysis, smoking history (OR .6, 95% CI .04-.08, $P=.005$) and preoperative aspirin use (OR .6, 95% CI .5-.9, $P=.004$) were protective against persistent/new type 2 endoleak, while bilateral hypogastric artery coiling was predictive (OR 8.3, 95% CI 2.8-24.9, $P<.001$). Aneurysm sac growth was more common in patients in group 2 among 202 patients with available follow-up data (38% vs. 15%, $P=.001$). Rates of graft migration, conversion to open repair, and development of symptoms/rupture were not significantly different. Of 153 total reinterventions, 90 occurred after discharge. Preoperative hypertension (OR 3.3, 95% CI 1.2-9.0, $P=.022$) and having a persistent/new type 2 endoleak were predictive of post-discharge reintervention (OR 2.1, 95% CI 1.2-3.5, $P=.008$). Persistent/new type 2 endoleak was not associated with survival (OR 1.3, 95% CI 0.9-2.0, $P=.130$). Factors associated with worse survival included

history of CHF (OR 1.6, 95% CI 1.0-2.4, P=.022), COPD (OR 1.4, 95% CI 1.0-1.9, P=.045), preoperative Cr >2.0mg/dl (OR 2.5, 95% CI 1.4-4.5, P=.003), being unfit for an open procedure (OR 1.6, 95% CI 1.1-2.3, P=.016), having an unanticipated graft extension (OR 2.2, 95% CI 1.3-3.9, P=.004), and not being discharged home (OR 1.8, 95% CI 1.1-3.0, P=.023).

Figure 1. Freedom from post-discharge reintervention.

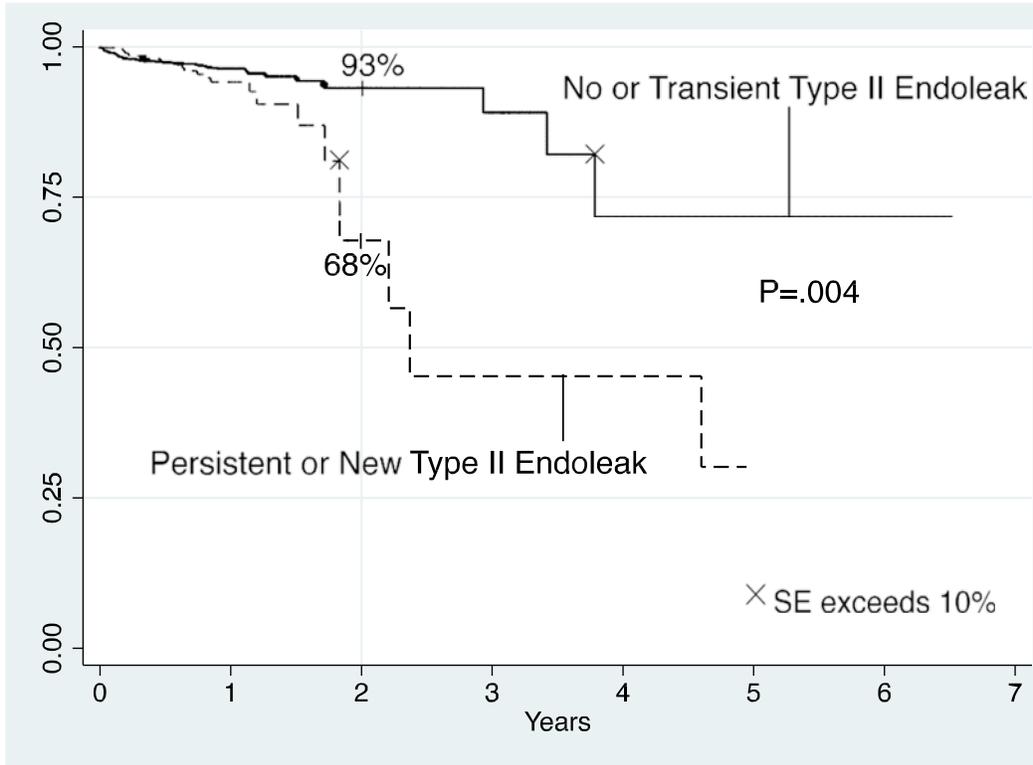
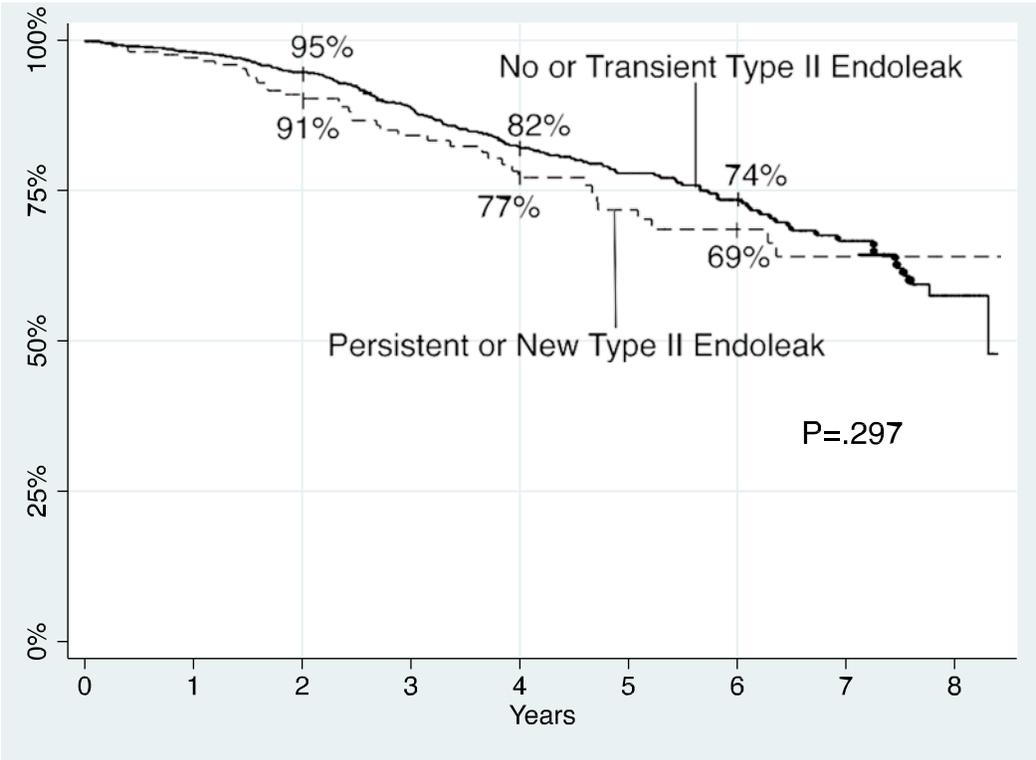


Figure 2. Survival.



Conclusion: Bilateral hypogastric artery coiling correlates with increased risk of developing persistent/new type 2 endoleak, while aneurysm size and gender do not. Persistent or new type 2 endoleaks are associated with an increased risk of sac growth and reintervention. This reinforces the need for continued surveillance of patients with persistent/new type 2 endoleaks, and may be cause for prophylactic intervention.

Basic Science, Clinical & Translational Research

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Retrospective Analysis of the Use of Routine Laboratory Monitoring in a Cohort of HIV Positive Patients

Introduction: Cost has become the focus of a national discussion of about the future direction of healthcare. With the advent of highly-active antiretroviral therapy (HAART) in the last few years HIV patients are living longer than ever before.¹ This increase in longevity has shifted the some of focus of HIV providers from managing acute issues and towards management of HIV as a chronic disease.² This shift in paradigm brings with it a need to optimize care to minimize the burden of the overutilization of routine testing on the patient the provider as well as the cost to the health care system. By identifying the optimal interval for routine testing cost can be reduced while maintaining quality of care.³⁻⁵

Objective: The objective of the study is to describe and evaluate the use of routine testing in the setting of a Ryan White funded HIV clinic in Denver, Colorado.

Background: There is a strong precedent of evaluating the use of routine tests in the setting of other diseases and conditions.⁶⁻⁸ In the HIV literature most work examining the benefit of routine lab monitoring has been done in resource poor setting with hope of expanding the use of anti-retroviral medications into settings where the facilities needed to obtain routine laboratory monitoring are unavailable.^{9,10} However, these same ideas could be applied in resource rich settings to attenuate the ever increasing costs of healthcare. Annual cost of care for HIV patients are was measured at \$2,772 and it is projected that the number of patients on HAART will continue to increase at least in the short term.^{1,11,12} Recently two small studies have been conducted with the objective of providing to demonstrate the need for further research into the identifications of ideal monitoring frequency.^{4,6} However, both of these studies had more stringent inclusion criteria and smaller sample sizes than in this study. In July the Antiretroviral Treatment of Adult HIV Infection 2012 Recommendations of the International Antiviral Society-USA Panel were published in JAMA. They noted that no work has defined the optimum frequency of monitoring despite the perception that such work could lead to cost savings.⁵

Methods: A retrospective chart review was performed with the aid of an electronic medical record. Patient with at least two visits to the infectious disease clinic and no hospitalizations were identified and information including age, race, ethnicity, HIV acquisition risk factor, time since diagnosis, number of lab tests in a given year, number of abnormal lab tests in a given year, values for CD4 count and viral loads, number of infectious disease visits, emergency visits, urgent care visits, where or not the patient was on HAART in a given year were collected electronically. Charts were then reviewed manually to ensure the validity of the data. Changes were made as errors were found. This

process continued iteratively until errors were not found in 20 consecutive charts. We defined well controlled patients as patients who had had no detectable viral loads in the last year, at least two viral loads in the last year and at least one CD4 count above 350 in the previous year. Charts that were determined to have clinically significant abnormal labs and 50 for each were further reviewed manually to determine if an action was taken as a result of the abnormalities.

Results: 654 eligible patients were identified in 2006, 681 were identified in 2007, 748 in 2008, 807 in 2009, and 866 in 2010. In 2007 149 patients met the criteria for being well controlled, in 2008 215 met the criteria in 2009 274 in 2010 332. Further results are pending.

Conclusion: Results will provide a description of the use routine laboratories in an HIV clinic and will provide information on the incidence of abnormal results in both the total population as well as a sub set of well controlled patients.

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Basic Science, Clinical & Translational Research

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Small Bowel Obstruction: A Decision Analysis

Introduction: Adhesional small bowel obstruction (ASBO) represents a major complication after lower abdominal operations. Despite the abundance of small bowel obstruction literature, the controversy between conservative management and immediate operative management of ASBO has not been resolved. A decision analysis comparing the two treatment plans has not yet been assessed.

Objective: To compare and assess health care outcomes between operative and conservative treatment of postoperative adhesional small bowel obstruction.

Background: Determining the optimal management of postoperative adhesional small bowel obstruction requires an assessment of morbidity, mortality, cost, quality of life, and successful outcomes in both operative and non-operative treatment plans. We used a decision and cost-effective model to simulate clinical and economic outcomes after treatment of an episode of adhesional small bowel obstruction to determine the preferable management strategy.

Method: A Markov model was constructed to evaluate mortality, morbidity, health care costs, quality of life, and small bowel obstruction recurrence rates associated with both operative management and conservative management of ASBO. Cost-effective analyses from a healthcare system perspective as well as a patient perspective were performed, using hypothetical cohorts of patients who recovered from lower abdominal surgery. Probabilities of events and costs for the base-case analysis were derived by an exhaustive literary search. Cost data was collected from an online Medicaid data base.

Results: A complete decision analysis is still under investigation. Data was extracted from over fifteen peer review articles and includes health care outcomes from over 10,000 patients. Recurrence of ASBO after operative treatment occurs at a rate of 25.43% vs. 40.57% after conservative treatment. Time to recurrence of ASBO after operative treatment occurs at a median time of 367 days vs. 194 days after conservative treatment. Hospital length of stay (LOS) after surgical management of ASBO is a mean 11 days vs. 4 days for conservative treatment. Mortality due to operative management of ASBO occurs at a rate of 6.4% vs. 5.2% due to conservative treatment. Complication rate due to operative treatment occurs at a rate of 23.3% after operative treatment vs. 2.3% after conservative treatment.

Conclusion: Preliminary data leads to believe that an operative treatment plan for small bowel obstruction is optimal; however, a complete decision analysis needs to be performed in order to make an accurate assessment.

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Basic Science, Clinical & Translational Research

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Simulating Hemolytic Conditions *in vitro* to understand the Cause of Hypoargininemia in Severe Malaria Infections

Introduction: Each year, malaria causes over 500,000 deaths, or about 7% of the deaths, in children under age five.¹ The clinical outcome of a child depends on parasite, host, and geographical and social factors, many of which are unfavorable in African nations.² To better understand the interaction of parasite and host factors, recent malaria research has focused on understanding the cause of fundamental aspects of malaria infections, such as endothelial dysfunction, metabolic acidosis, and hypoargininemia, all of which predispose children to life-threatening disease, including cerebral malaria.

Objective: To examine the degradation of L-arginine (L-arg) in various *in vitro* conditions to better understand the cause of hypoargininemia in severe malaria infections.

Background: One prevalent assumption in recent research is that hypoargininemia in severe malaria is caused, at least in part, by hemolysis and the subsequent release of arginase, a manganese-dependent enzyme that catalyzes the conversion of L-arg into L-ornithine and urea.^{2,3} Understanding the nature of hypoargininemia in severe malaria infections could be important in developing better therapeutics for the disease.

Methods: Fresh blood was collected into lithium heparin tubes, centrifuged, and separated into plasma and packed red blood cells (pRBC) in three volunteer subjects. An aliquot of pRBC was lysed using needle aspiration, whereby the cells were lysed by shear stress by repeatedly drawing them through a thirty-gauge needle. Baseline measurements of L-arg were obtained from plasma and the supernatant of lysed pRBC samples. Four experiments were conducted as follows: (1) a 3:1 mixture of plasma and pRBC (25% hematocrit) were combined and incubated at 37 °C for four hours; (2) a 3:1 mixture of plasma and pRBC were combined, the cells were lysed by needle aspiration, and the mixture was incubated; (3) separate samples of plasma and pRBC were incubated; and (4) plasma alone and a 3:1 mixture of plasma and pRBC were supplemented with three fold excess manganese and were incubated. After incubation, samples were centrifuged, and aliquots of plasma and pRBC were collected. The pRBC were then lysed using needle aspiration. L-arg concentration was measured using high performance liquid chromatography (HPLC) using *o*-phthalaldehyde (OPA) to tag the primary amines of free amino acids.

Results: At the time of submission, sample measurements of L-arg were not complete, and consequently no results are available at this time. Upon receipt of these data, I will firstly determine the relative contribution of the RBC and plasma compartments in the depletion of free L-arg.

Secondly, I will compare the depletion of L-arg in the lysed experiment to determine if disrupting the membrane affects L-arg depletion. Finally, I will assess whether manganese supplementation affects the specific activity of arginase.

Conclusion: Hypoargininemia is a risk factor for cerebral malaria in severe malaria. Understanding the cause of hypoargininemia could reveal new methods for mitigating serious complications of the infection. Here, *in vitro* experiments were conducted to determine the contribution of hemolysis in depleting free L-arginine. At the time of abstract submission, no results were available to draw conclusions.

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Basic Science, Clinical & Translational Research

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Quality Assurance for Pediatric Patients in the Comprehensive Psychiatric Emergency Program

Introduction: Quality assurance is an important component of health care research. Patients' experiences at every point in their hospital stay have the potential to affect overall outcomes. At the Comprehensive Psychiatric Emergency Program (CPEP) at Strong, a new child and adolescent waiting area will open in the fall/winter of 2012. Considering the sensitive and urgent nature of psychiatric emergencies in children, quality factors should be considered in the planning of the new waiting area in order to adhere to a patient- and family-centered approach.

Objective: The present study aimed to determine what quality factors are important to pediatric patients and families who visit the CPEP. This information will be used to inform the planning of the new child and adolescent waiting area.

Background: Specific quality factors that are important to patients have been previously identified for children in general emergency rooms (Tracy, 2007; American Academy of Pediatrics, American College of Emergency Physicians, & Emergency Nurses Association, 2009). Additionally, the quality factors that affect adults' experiences with psychiatric emergency services have been identified (Jayaram & Triplett, 2008; O'Regan & Ryan, 2009). However, no studies have examined the quality factors that are important to children and their families in specialized psychiatric emergency waiting rooms.

Methods: Based on previous work (Jayaram & Triplett, 2008; Woo & Sultzer, 2009), several anticipated concepts were identified. To minimize additional stress on the pediatric patients, we chose to interview parents of the patients. Qualitative interviews consisting of a series of open-ended questions were administered to 15 parents or legal guardians of pediatric patients seen in the CPEP during June and July 2012. Only those parents/guardians who lived with the patient, spoke English fluently and were considered to have capacity to give verbal consent for participation were included in the study. However, one participant was interviewed with the assistance of an American Sign Language interpreter. Demographics and self-report questionnaires were also administered.

Results: Many but not all of the anticipated concepts and themes were identified as important by the parents/guardians in the open-ended interview. Concepts identified from the interview responses included, in order of frequency: wait time, entertainment/relief from boredom, comfort, staff, safety, food, privacy and effectiveness of care. The importance of these concepts is supported by quotes from the interviews.

Conclusion: The separate waiting area for children will be a welcome change to the CPEP. For the most part, parents are satisfied with their experience in the CPEP. The new waiting area should contain sources of entertainment and relief from boredom to reduce perceived wait time. Having literature about community mental health resources available in the waiting area could provide relief from boredom as well as caregiver education. Other suggestions from the caregivers included more televisions, more hands on toys, tables and colorful wall murals.

Parents and guardians were comfortable for the most part. However, they did desire a warmer and less clinical environment and a place to sleep for overnight waits. Specifically, participants desired easier access to food and coffee for the families of the patient.

Parents were also concerned about privacy and safety. Many of the guardians were pleased to hear that the children will be separate in the new waiting area, as exposure to the adult patients was a common source of concern. Privacy was also important and families preferred to wait in their own, private interview rooms.

Limitations to this study include the lack of input from the pediatric patients themselves and the relatively small number of caregivers who were interviewed.

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Basic Science, Clinical & Translational Research

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Hyperuricemia in Chronic Kidney Disease: Uric Acid in the CKiD Cohort

Objective: The Chronic Kidney Disease in Children Prospective Cohort Study (CKiD) was used to determine if hyperuricemia is associated with hypertension in pediatric CKD.

Background: Hyperuricemia is traditionally associated with gout, nephrolithiasis, disorders of purine metabolism, renal failure, and use of diuretics. Synthesized in the liver, 65-75% of the body's uric acid load is eliminated by the kidneys where renal filtration and secretion are partially opposed by proximal tubular reabsorption. [1]. Urate serum values increase during development and are comparable in males and females until puberty (12-14 y), beyond which normal values in males are higher [2]. Epidemiologic studies in adult populations have associated hyperuricemia with DM Type II, cardiovascular disease, metabolic syndrome, essential hypertension, and renal progression [3-7]. Compared to the adult data, a smaller body of evidence indicates that hyperuricemia is associated with essential hypertension in adolescents [8]. Animal models suggest hyperuricemia causes hypertension via afferent arteriolar thickening and vascular smooth muscle proliferation [9].

Methods: Cohort 1 and 2 subjects with concurrent serum uric acid and ieGFR (iohexol or estimated) measurements at annual visits 1 through 4 were included for this cross-sectional analysis. Data was plotted as log(ieGFR) vs. serum uric acid. Uric acid values of patients with hypertension (defined as systolic or diastolic >95% for age-gender or use of anti-hypertensive medication; patients taking diuretics were excluded) were compared to those of normotensive patients at an ieGFR of 60 mL/min/1.732m². This analysis was conducted for three different age-gender strata: 1) all males and females together; 2) all females and pre-pubertal males (age < 13 y); and 3) post-pubertal males (age > 13 y).

Results: Visit 1-4 Serum UA in Hypertensive vs. Normotensive Subjects at ieGFR of 60 mL/min/1.732m²

Group	Uric Acid Surplus in HTN	Hypertensive (N)	Normotensive (N)	p-value
Males/Females Together	0.36 mg/dL	522	293	0.0022
Females and Males < 13 y	0.38 mg/dL	372	222	0.0020
Males > 13 y	0.42 mg/dL	150	71	0.11

Conclusion: Females and pre-pubertal males (age < 13 y) with hypertension have uric acid values that are significantly higher than those without hypertension at an ieGFR of 60 mL/min/1.732m². Uric acid, therefore, could contribute to hypertension early in the course of CKD in this demographic. It is plausible that hyperuricemia could hasten the progression of CKD via uricemia-induced essential hypertension, serving, therefore, as a modifiable risk factor. A follow-up longitudinal analysis is planned to answer this question.

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Basic Science, Clinical & Translational Research

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A Qualitative Exploration of ED Readmissions by Older Adults

Introduction and Background: Compared to younger people, older patients use emergency departments (ED) at a higher rate, are more likely to return for ED care, and experience higher rates of adverse outcomes after discharge.¹ Recent research indicates that transition of care between the ED and community has significant patient safety and quality deficiencies.²

Objective: To gain a greater understanding of post-discharge factors that impact ED readmissions of older adults.

Methods: We performed a qualitative study of older adults (age \geq 65) who were either being discharged home from the SMH ED or who were returning to the SMH ED within 30 days of previous ED care. We interviewed 36 subjects, 18 who were being discharged and 18 who were being readmitted to the ED. A grounded theory of analysis was conducted using transcribed interview responses to build up a distinctive series of themes and codes.

Results: Major codes that arose from the preliminary analysis include: accessing care, connections and relationships, managing health, biomedical issues and need for care, notions of autonomy, interactions with the health care system, interactions with health care providers, perceptions of health, cost and financial issues, transportation and driving, social and environmental constraints, social supports to health, and aging.

Conclusion: Preliminary analysis suggests that access to primary care and social supports plays a major role in the decision to return to the ED and the ability to transition home successfully. A complete analysis and additional research will help to confirm and triangulate these findings.

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Basic Science, Clinical & Translational Research

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Etiology of differential expression of novel markers for plaque instability

Introduction: The majority of cardiovascular deaths are the result of disruption or rupture of the fibrous cap of an unstable, lipid laden atherosclerotic plaque. This makes the confirmed presence of an unstable plaque in a patient a useful indicator of their risk for a future cardiovascular or cerebrovascular event. However, current strategies for distinguishing a plaque as unstable fall short, with a large number of plaques being identified as unstable only by the patient experiencing an acute event. This study is aimed at identifying intraplaque markers of instability with the goal of extrapolating these proteins as serum biomarkers. Plaques that are considered likely to rupture or clot and cause an acute clinical event are classified as unstable, and the properties that characterize such a plaque are extensively described in the literature. However, the natural history of plaque progression and destabilization remains largely unknown.

Background: Various inflammatory markers have been shown to play a role in the pathological progression of atherosclerosis, one being tumor necrosis factor- α (TNF- α). This inflammatory protein is responsible for the recruitment and activation of inflammatory cells, and upregulation of adhesion molecules on the arterial endothelium. The inflammatory proteins tissue factor (TF) and thrombospondin-1 (TSP-1) have also been shown to play a role in destabilization. In addition to these inflammatory markers, a number of proteolytic enzymes have been implicated in the progression of the vulnerable plaque disease process. These include matrix metalloproteinase-2 and -9 (MMP-2 and MMP-9), primary regulators of the extracellular matrix. MMP-2 and MMP-9 have been localized to the shoulder region of plaques and their levels have been shown to be higher in unstable plaques. Also of note are regulators of the conversion of plasminogen to plasmin: uPA, tPA, and PAI-1, which have also been the focus of recent research in the field.

Objective: To identify intraplaque biomarkers of atherosclerotic plaque instability. We hypothesized that comparison of plaques from symptomatic patients to those from asymptomatic patients would show differences in proteolytic and inflammatory proteins, identifying them as markers of an unstable plaque.

Methods: 42 patients (22 women, 20 men, age range 52-89 years) presenting to Vascular Surgery at Strong Memorial Hospital with carotid artery stenosis (symptomatic: stroke, TIA or transient monocular blindness -or- asymptomatic: >70% stenosis) and no other vascular diseases were entered into this study after informed consent was obtained. For data analysis, individual samples from

asymptomatic patients were compared to those of symptomatic patients. Each pair was matched by their age, gender, and presence or absence of chronic statin therapy. All plaques were obtained after endarterectomy and following protein extraction, the expression of proteolytic enzymes (uPA, tPA, PAI-1 and MMP-2) and inflammatory markers (TF, TSP-1, and TNF- α) were evaluated by Western blot analysis. The housekeeping gene GAPDH was used as a positive control to ensure that an equal amount of protein was loaded into each well.

Results: The intraplaque expression of proteolytic enzymes tPA and uPA were 5.9x and 4.5x higher ($p < .05$) respectively, in the symptomatic group than in the asymptomatic group. The symptomatic group also showed a 4.3x increase in active MMP-2 and a 3.6x increase in PAI-1 expression. Investigation of inflammatory proteins demonstrated a marked increase in their expression, with 2.7-, 4.7-, and 3.3-fold increases in the expression of TNF- α , TSP-1, and TF, respectively.

Conclusion: The demonstration of elevated expression of certain inflammatory markers and proteolytic enzymes in carotid plaques from symptomatic patients leaves promising avenues for further inquiry into their roles in atherosclerotic disease and their potential as clinically detectable biomarkers of an unstable atherosclerotic plaque.

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Basic Science, Clinical & Translational Research

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Cost Analysis of Objective Resident Cataract Surgery Assessments

Introduction and Background: In 1998, the American Council for Graduate Medical Education (ACGME) began a national and cross-specialty “Outcome Project” to improve the education and documented training of residents. Ophthalmology programs quickly responded by developing a variety of objective and timely surgical assessment tools. Assessments came in the form of operative outcome measures, video assessments, wet laboratories, virtual reality simulators, motion analysis systems, procedure checklists and global rating scales.¹ Meeting the ACGME’s mandates required significant changes to curriculum and the amount of time faculty spent with residents. Since 2007, the ACGME has required that “a surgical skills development resource (e.g., a wet lab or simulators) must be available” to residents.² The setup of a wet lab or surgical simulator requires substantial funding. The increase in spending paired with the proposed cuts in GME funding forces residency programs to now consider the cost-effectiveness of particular training and assessment tools.^{3,4}

Objective: The aim of this study was to determine the costs associated with eight cataract surgery assessment tools that are currently in use, and have proven to have a degree of reliability and/or validity. The 8 tools evaluated were: Eye Surgical Skills Assessment Test (ESSAT),^{5,6} Iowa Ophthalmology Wet Laboratory Curriculum (OWL),⁷ Human Reliability Analysis of Cataract Surgery (HRACS),⁸ Objective Assessment of Skills in Intraocular Surgery (OASIS),⁹ Global Rating Assessment of Skills in Intraocular Surgery (GRASIS),¹⁰ Objective Structured Assessment of Cataract Surgical Skill (OSACSS),¹¹ Imperial College Surgical Assessment Device (ICSAD),¹² EyeSi Cataract Surgery Simulator.¹³⁻¹⁵

Methods: For each assessment tool, costs were divided into Initial (one time purchases: cost of wet lab, cameras, microscopes, simulators), Annual (recurring costs: supplies, rent, time associated costs) and First Year (Initial costs + Annual costs) categories. Initial and Annual costs were determined from price quotes by medical supply companies and Flaum Eye Institute’s Finance department. Time Associated Costs were those relating to the value of faculty’s time. Faculty-associated costs were determined by multiplying the hourly wage of an attending ophthalmologist by the amount of time spent implementing each assessment tool. The times required to implement each assessment tool were calculated through literature search, and feedback from faculty. Qualitative analysis of each assessment tool was completed based on the level of involvement required of the attending. “Low involvement” (pre-determined criteria and a Likert scale), “Medium involvement” (pre-determined criteria with partial free response) and “High involvement” (free-standing evaluation) were determined for each assessment tool.

Results:

	ESSAT	OWL	HRAC S	OASIS	GRASIS	OSACSS	ICSAD	EyeSi
Assessment Type	Wet Lab	Wet Lab	Video	Intra-surgery	Post-surgery	Video	Motion tracking	Virtual reality
Level of Attending involvement	Low	Low	Low	Medium	Low	Low	Low	Low
Initial Cost (\$)	326,400.00	326,400.00	4,900.00	0.00	0.00	4,900.00	12,000.00	169,000.00
Annual Cost (\$)	59,834.91	59,581.45	990.79	990.79	990.79	990.79	1,797.25	21,322.25
First Year Cost (\$)	386,234.91	385,981.45	5,890.79	990.79	990.79	5,890.79	13,797.25	190,322.25

Conclusion: In addition to providing timely, quantitative and qualitative feedback, assessments must have reasonable time and financial costs. This study presented the quantitative and qualitative costs commonly associated with eight tools. With these direct comparisons, costs of a particular tool can be linked to downstream quality measures, and a cost-effectiveness model can be designed. As future research addresses cost effectiveness, programs can make informed decisions as to how particular education tools affect the learning and cost curves.

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Basic Science, Clinical & Translational Research

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Corneal and Eyelid Abnormalities in the *Bim*^(-/-) Mouse Model

Introduction: The cornea is the clear “windshield” to the eye that performs the dual function of providing clear optical quality and light access to the interior of the eye and serving as a barrier between the internal eye structures and external environment.¹ The healthy cornea maintains ocular transparency by utilizing a sustained “angiogenic privileged” state that suppresses inflammation, immune reactions and vascularization.² When the cornea sustains injury or insults, chronic inflammatory reactions are stimulated, leading to neovascularization and subsequent fibrosis or scarring of the corneal tissue.^{1,2} While strong fibrosis accompanying new vessels may be beneficial in nonocular tissues, fibrosis in ocular tissues leads to refractive aberrancies as well as physical impedance, consequently impairing vision and compromising the functional clarity of the cornea.¹ Distichiasis is a rare ocular disorder defined as the abnormal growth of eyelashes from the orifices of the meibomian glands of the upper and lower eyelids. These aberrant lashes can protrude onto the surface of the cornea, causing irritation, epiphora, and severe corneal abrasions and ulcers.³

Objective: The objective of this project was trifold: 1. To identify and characterize corneal and eyelid abnormalities in *Bim*^(-/-) mice 2. To understand the role of apoptotic proteins in the development of corneal and eyelid abnormalities in *Bim*^(-/-) mice and 3. To understand the utility of the mouse model for anterior segment research.

Background: Mice have emerged as viable models for conducting ocular anterior segment research.⁴ While there are obvious, documented disparities between mice eyes and human eyes, the ability to understand the molecular mechanisms behind eyelid development, corneal fibrosis, scarring and neovascularization is facilitated by the use of different genetic strains of mice.

Mouse eyelid development follows a well-established timeline during embryonic development.⁵⁻⁷ On embryonic day 9 (E9) of development, the eyelid tissue is specified. At E11.5, the eyelid tissue begins to grow with the invagination of the dorsal and ventral periocular ectoderm. Between E11.5 and E15.5, the upper and lower eyelids begin to grow across the surface of the developing eye. At E15.5, the upper and lower eyelids fuse and remain closed until post-natal day 10 (P10), when the eyelids separate. When the eyelids are closed, the eyelid epithelium differentiates into the palpebral epidermis, the outer surface of the eyelid, and the palpebral conjunctiva, the inner surface of the

eyelid. The palpebral epidermis differentiates as part of the skin and the hair follicles of the eyelashes form at the upper and lower lid margins. At birth, the meibomian glands form by ingrowth of conjunctival epithelial cells at the inner surface of the lid margins.⁵⁻⁷

Mammalian apoptosis, the genetic program of cell death, is facilitated by the interplay of proapoptotic proteins (BAX and BAK) and antiapoptotic proteins, (BCL-2, BCL-XL, and MCL-1). Apoptotic signals release cytochrome-c from the mitochondria into the cytoplasm to activate the Apaf-1 protein that ultimately activate caspases, enzymes that execute cell death. A third subfamily of proteins, the activator, BH3-only molecules (BIM, BID and PUMA), are thought to promote apoptosis either by activating BAX and BAK or inactivating BCL-2, BCL-XL, and MCL-1. Ren et. al in 2010 found that BIM, BID and PUMA are essential activators of BAX and BAK and the mitochondrial apoptosis program by using *Bid*^(-/-), *Bim*^(-/-), *Puma*^(-/-) triple-knockout mice. ⁸

With this information, mice from three different backgrounds (C57BL/J6, DBA/2J and Bid, Bim, Puma), in whom the BIM protein was deleted (*Bim*^(-/-)), were used as models to identify and characterize eyelid and corneal abnormalities and understand the role of apoptosis in the development of these abnormalities.

Methods: Cornea and Eyelid Characterization: Three strains of mice were selected for examination, C57BL/J6, DBA/2J and Bid, Bim, Puma, due to previous observations of gross corneal abnormalities. Within these strains of mice, mice in whom the BIM protein was deleted (*Bim*^(-/-)) and wildtype mice (*Bim*^(+/-), *Bim*^(+/+)) in whom the BIM protein was intact, were observed. A null allele for *Hrk 57*, another BH3-only protein that is known to facilitate, but not add to BIM function, was also present in the D2 mice. 60 *Bim*^(-/-) mice (120 eyes) within these three strains (10 B6, 20 D2, and 30 Bim, Bid, Puma), were examined. 60 wildtype mice (120 eyes) within these three strains (9 B6, 21 D2 and 30 Bim, Bid, Puma) were observed as controls. All mice were examined under a surgical, dissecting scope by one observer for gross corneal and eyelid abnormalities. Corneal and eyelid phenotypes were noted and slit-lamp photographs were obtained of all phenotypes.

Immunohistochemical Staining: To understand the role of apoptosis in mouse eyelid development, previously cut sections of wildtype, embryonic mice eyes at ages E14.5, E17.5 and E18.5 were immunohistochemically stained with Caspase-3, BCL- XL, and BIM antibodies, markers of apoptosis.

Results: Cornea and Eyelid Characterization: The abnormal corneal and eyelid phenotypes viewed upon examination were cloudy cornea, cloudy cornea with vascularization, corneal ulcer, distichiasis, and distichiasis with cloudy and vascular cornea. Among all three strains of *Bim*^(-/-) mice, 22 of 120 eyes (18.3%) had abnormal corneal and eyelid phenotypes. When stratified by strain, 0 of 20 eyes (0%) in the B6 strain, 17 of 40 eyes (42.5%) in the D2 strain and 15 of 60 eyes (25%) in the Bim, Bid, Puma triple strain had abnormal phenotypes. When stratified by abnormal phenotypes among all three strains of mice, 8 of 120 eyes (6.7%) had cloudy corneas, 5 of 120 eyes (4.2%) had cloudy corneas with vascularization, 2 of 120 eyes (1.7%) had corneal ulcers, 2 of 120 eyes (1.7%) had distichiasis, and 15 of 120 eyes (12.5%) had distichiasis with cloudy and vascular corneas. Among all three strains of wildtype *Bim*^(+/-), *Bim*^(+/+) mice, 9 of 120 eyes (7.5%) had abnormal corneal and eyelid phenotypes. When stratified by strain, 0 of 60 eyes (0%) in the B6 strain, 6 of 60 eyes (10%) in the D2 strain, and 3 of 60 (5%) of the Bim, Bid, Puma triple strain had abnormal phenotypes. When stratified by abnormal phenotypes among all three strains of control mice, 2 of 120 eyes (1.7%) had edematous, erythematous upper and lower eyelids, 1 of 120 eyes (.83%) had a

cloudy cornea, 1 of 120 eyes (.83%) had a cloudy cornea with vascularization, and 5 of 120 eyes (4.2%) had distichiasis with a cloudy and vascular cornea.

Breakdown of presence of phenotypes

Strain	Number of eyes	Percentage of eyes with abnormal phenotypes
Experimental		
Black 6	0/20	0%
D2	17/40	42.5%
Bim, Bid, Puma TKO	15/60	25.0%
All strains	22/120	18.3%
Control		
Control Black 6	0/60	0%
Control D2	6/60	10%
Control Bim, Bid, Puma TKO	3/60	5%
All strains	9/120	7.5%

Breakdown of abnormal phenotypes among all 3 strains

Phenotype	Number of eyes	Percentage of eyes
Cloudy Cornea	8/120	6.7%
Cloudy and Vascular Cornea	5/120	4.2%
Ulcer	2/120	1.7%
Distichiasis	2/120	1.7%
Distichiasis, Cloudy and Vascular Cornea	15/120	12.5%

Breakdown of abnormal phenotypes among control mice of all 3 strains

Phenotype	Number of eyes	Percentage of eyes
Edematous, Erythematous lids	2/120	1.7%
Cloudy Cornea	1/120	.83%
Cloudy and Vascular Cornea	1/120	.83%
Distichiasis, Cloudy and Vascular Cornea	5/120	4.2%

Immunohistochemical Staining: Preliminary immunohistochemical staining of sectioned embryonic eyes at ages E14.5, 17.5, and 18.5 showed no evidence of apoptotic activity. There was no Caspase-3, BCL-XL or BIM expression in the upper and lower eyelid tissues during the different stages of eyelid development.

Conclusion: Our preliminary immunohistochemical staining results indicate that apoptosis does not play a role in eyelid tissue development at ages E14.5, E17.5 and E18.5. We cannot associate the development of aberrant lashes in the *Bim*^(-/-) mice to the absence of the apoptotic pathway protein BIM. Our findings do however indicate that DBA/2J and Bid, Bim, Puma triple strain *Bim*^(-/-) mice are susceptible to corneal clouding and vascularization and distichiasis, however these phenotypes

are not completely penetrant. The C57BL/J6 *Bim*^(-/-) mice strain did not develop any corneal or eyelid abnormalities. While we initially thought that the aberrant lashes were causing insults to the cornea and subsequent abnormalities, corneal clouding and vascularization were observed independent of the abnormal eyelashes in a subset of mice. This has led us to believe that the eyelid and corneal abnormalities are occurring separately and are not necessarily linked.

Future Directions:

1) Future work will include longitudinal observation of DBA/2J and C57BL/J6 *Bim*^(-/-) and wildtype (*Bim*^(+/-), *Bim*^(+,+)) mice at postnatal day 14-21 (the time at which the eyelids open and the meibomian glands have formed), 1 month, 3 months, 6 months, 9 months and 1 year, to detect the development and/or progression of eyelid and/or corneal abnormalities between the two different strains.

2) *Bax/Bak*^(-/-) mice, mice in whom all apoptotic proteins have been deleted, will also be observed longitudinally to observe the development of eyelid and/or corneal abnormalities and determine if abnormal eyelid and corneal development is independent of the apoptotic pathway.

3) Corneas will be removed from previously observed DBA/2J and Bid, Bim, Puma triple strain *Bim*^(-/-) mice in whom no corneal or eyelid phenotypes were observed, flat-mounted and immunohistochemically stained for vascular basement membrane markers (collagen IV and α -SMA) to characterize any subclinical differences in corneal limbal architecture that may predispose these mice to corneal clouding and vascularization.

4) To study the mechanism of wound healing in the *Bim*^(-/-) mice, corneal injury will be induced and wound-healing will be observed and compared to previously reported timelines and processes of corneal angiogenesis and fibrosis.

5) Lastly, further immunohistochemical staining can be performed on eyelid tissue from wildtype and *Bim*^(-/-) mice at post-natal days 10-14 to see if apoptotic activity is present during the formation of the meibomian glands and if the lack of apoptotic activity causes abnormal meibomian gland development and the onset of distichiasis.

Understanding the mechanisms and pathways of distichiasis, corneal angiogenesis, fibrosis and wound-healing will allow for the development of targeted interventions and therapies uniquely capable of reducing the burden of illness related to abnormal corneal vessel growth and scarring and can ultimately lead to lower rates of blindness and improved visual function in both humans and animals.

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Basic Science, Clinical & Translational Research

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Explaining Sex Differences in Batten Disease: Parents' Sex Bias and Estrogen

Introduction: Juvenile Neuronal Ceroid Lipofuscinoses (JNCL; Batten disease) is a neurodegenerative disease with typical onset between 4 and 8 years of age. Vision loss is often the first symptom, followed by seizures, dementia, behavioral difficulties, and motor impairment occurring between 10 and 12 years, and progression to death by the third decade of life.¹ Inheritance of JNCL follows an autosomal recessive pattern. However, differences in onset and progression of the disease in males versus females have been observed. Females experience JNCL symptom onset one year later, yet experience earlier loss of independence in performing activities of daily living (ADL's) and die one year earlier on average than do males.²

Objective: The focus of this project was to establish an explanation for the sex differences observed in the onset and progression of JNCL. Two explanations for the differences observed between males and females were tested: (1) the presence of a sex-based bias in parental assessment of physical ability in JNCL affected individuals and (2) elevated estrogen levels in serum samples of females with JNCL.

Background: The reason for the sex-based differences in JNCL onset and progression is currently unexplained. The differences observed may be a result of parental bias in regards to engendering activity level and physical capability. Mothers of female infants have lower expectations for their daughter's ability to perform motor tasks while they overestimate their son's performance.³ Additionally, mothers of school-age children give daughters more cautionary warnings when they engage in injury-risk behavior.⁴ Higher estrogen levels in JNCL females may also be responsible for the observed differences. In diseases with autoantibody processes, higher estrogen levels are related to worsening autoimmune responses.⁵ Autoantibodies to GAD65, an enzyme that converts glutamic acid to g-aminobutyric acid (GABA), an important neurotransmitter, have been found in the CNS of mouse models and human JNCL.⁶

Methods: Parental rating. Parents of affected JNCL individuals completed the PedsQL parent proxy questionnaire, version 4.0.⁷ The relationship between gender, the PedsQL physical subdomains scores, and the motor score assigned by a pediatric neurologist during administration of the Unified Batten Disease Rating Scale exam (UBDRS)¹ was assessed using factorial ANOVA. Estrogen levels. Serum was collected from three females with a diagnosis of JNCL and seven unaffected females with a JNCL sibling. The estradiol content of serum was analyzed by tandem mass spectrometry at ARUP Laboratories in Salt Lake City, UT. Age of menarche, description of menses, and use of estrogen-based contraception were collected for each of the females who provided serum.

Results: Parental rating. There was a significant difference in boys vs. girls in three subdomains of physical activity as assessed by PedsQL vs. UBDRS: sports ($F_{4,72}=3.23$, $p=0.02$), low energy ($F_{4,72}=3.75$, $p=0.06$), and running ($F_{4,73}=2.54$, $p=0.06$). For each of the three significant physical subdomains, as the boys' UBDRS motor scores increased, so did the PedsQL score. The UBDRS ratings for the females remained relatively constant as the PedsQL subdomain ratings increased to reflect worsening physical functioning.

Estrogen levels. Early menarche was defined as menstruation beginning before age 12.8 Of the females with JNCL studied, 50% experienced early menarche, and 43% of the female siblings also experienced early menarche. Estradiol levels in the serum of two of the three JNCL females and the seven female siblings were low for their phase in their ovarian cycle, with levels ranging from 24.5-40.4 pg/mL for the samples provided during the early/mid-follicular phase, and 38-83.1 pg/mL for the late follicular phase samples.

Conclusion: Parental rating. These preliminary results demonstrate that there are differences in the parental rating of JNCL males' physical functioning vs. JNCL females' physical functioning. Parental assessment of JNCL males appeared to reflect the neurologist-assigned motor scoring, whereas parental rating of JNCL females did not appear to correspond with the neurologist ratings. Future aims of this project include analysis of potential gender biases in parents' decision-making process for how and when to initiate the use of mobility aids for their JNCL-affected child.

Estrogen levels. The estrogen levels for the majority of the subjects of the study were low, a finding that opposes the original hypothesis. Increasing the number of subjects and adding positive controls will help to differentiate whether or not these unexpected results were due to errors in sample handling.

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Basic Science, Clinical & Translational Research

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Progesterone as Predictor of Outcome after Mild Traumatic Brain Injury

Introduction: Clinical research indicates that women have worse outcomes than men after traumatic brain injury (TBI),¹ but only during childbearing years,^{2,3} raising the possibility that sex hormones are responsible for the differential outcomes. Progesterone, in particular, has received much attention as a possible treatment for TBI, with promising results from two Phase II clinical trials.^{4,5} Progesterone's positive effects on TBI outcomes may be reconciled with the worse outcomes for women by evidence suggesting that the hypothalamic-pituitary-gonadal axis is disrupted by TBI, causing a sudden decrease in sex hormones.⁶ This change from high progesterone concentration to low concentration may therefore explain the poor outcomes seen in women of childbearing age.

Objective: The primary objective of this study was to determine whether progesterone concentration in women immediately after injury predicts mild TBI (mTBI) outcomes.

Methods: This study used retrospective data from 787 mTBI patients recruited from six emergency departments in New York and Pennsylvania between 2008 and 2010. Subjects were included in the current study if they were female, between the ages of 16 and 60, and had follow-up data from the parent study (n=189). Women who reported taking a form of synthetic progestin were included in a "synthetic progestin" (SP) group (n=35), and their serum was not analyzed. Banked serum was analyzed for FSH concentration if women reported as post-menopausal or for women over 45. FSH concentration > 15 mIU/mL excluded women from the study (n=45). The serum was analyzed for progesterone concentration in all other women. Subjects were then classified by phase of menstrual cycle into 1) "Follicular Phase" (FP), based on progesterone concentration <2 ng/mL (n = 72), or 2) "Luteal Phase" (LP), with progesterone concentration >2 ng/mL (n=37). Outcome variables were completed 1 month after injury and included the Rivermead Post Concussion Questionnaire (RPCQ) and the EuroQol/EQ5D, a quality of life measure.

Results: There were 144 patients included in the study, 35 in the SP group, 72 in the FP group, and 37 in the LP group. Patients with high progesterone concentration at time of injury (LP group) performed worse on all outcome measures than patients with low progesterone levels (FP group) or patients taking synthetic progestins (SP). The mean RPCQ score was 11.17 for SP, 13.82 for FP, and 15.62 for LP (p = .1464). The mean EuroQoL index score was 0.8663 for SP, 0.8168 for FP, and 0.7403 for LP (p = .0106). The EuroQol General Health Rating was 77.14 for SP, 75.32 for FP, and 65.14 for LP (p = .0357).

Conclusions: The data support the hypothesis that the change from a high concentration to a low concentration of progesterone after head injury may lead to worse outcomes. Women in the luteal

phase of their menstrual cycles, when progesterone concentration is high, had worse outcomes than women in the follicular phase, when progesterone concentration is low or women taking synthetic progestin, which would maintain a constant, high level of progesterone. These findings have important implications for using progesterone as a treatment for mTBI, and for prognosis after mTBI. Future research should explore the change in progesterone concentration over time after injury in order to strengthen these findings.

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UR Street Outreach

Introduction: Last summer, UR Street Outreach was established in response to the serious lack of social and medical resources available to the unsheltered homeless population of Rochester, NY. The organization's initial goals were to reach out to this population, build trust and provide medical care that would address the population's unique medical and psychosocial needs. Over the past year, UR Street Outreach has grown tremendously, providing outreach and building relationships with homeless people living on the streets, sending out medical teams of physicians and students to provide point of contact treatment, and beginning to establish partnerships with other individuals and organizations in the Rochester area that serve the homeless.

Objective: As summer interns with the organization, we set out to continue building upon the outreach efforts of the past year, further expand our network of both medical and social service providers and to better focus the role that we as medical students can assume within these networks to provide the most efficient and effective care to the homeless patients that we serve.

Background: The unsheltered, or street, homeless are those people who do not utilize the shelter system, and reside outdoors for most or all of the year. People in this population, who are often dealing with severe substance abuse and mental health issues, and chronically live in harsh conditions, often fall through the cracks of existing social safety nets and are among the most vulnerable people in the city of Rochester. The unsheltered homeless that UR Street Medicine Outreach works with face unique challenges and barriers to services, and require solutions that reach outside traditional models of care. UR Street Medicine Outreach was created to provide drastically needed outreach that bridges the disconnect between the unsheltered homeless and the medical establishment and to provide holistic solutions that understand and address the unique health and psychosocial needs of this population.

Methods and Results: One of our priorities this summer was to ensure that UR Street Outreach was working to enhance the care that the homeless in Rochester receive, rather than simply duplicating already existing parallel systems of care. To address this concern, we reached out to and met with several organizations this summer throughout the community. Flowing from this outreach is a revised and enhanced organizational model that integrates key partnerships with local homeless healthcare service providers and social service outreach programs. Within this partnership, UR Street Outreach will continue to conduct evening "street rounds," and will fill the roles of initial outreach

and provision of acute medical care when necessary, and will serve as the bridge in providing access to more comprehensive homeless health care and social service programs.

Our efforts this summer also yielded several other valuable improvements to the organization. We established a relationship to ensure next-day appointment slot availability at Unity Health for patients whom we visit on evening rounds. Additionally, we coordinated our care at House of Mercy with an existing mobile medical van, such that one of us will be providing care every week. Other areas of development, including projects to develop training and education for medical students throughout the year, further development of our Outreach Resource Guide, ordering hygiene kits, conducting an initial focus group for needs assessment, will compliment existing efforts to address the needs of the unsheltered homeless.

Conclusion: The spark of vision and compassion provided by the founding leadership last year propelled UR Street Outreach into existence. By expanding our network of medical and social service providers this summer, we hoped to clarify and build upon the mission of UR Street Outreach, in the spirit of Meliora. The development of key collaborations within the community was a primary success of our efforts. Combining this with practical tools and opportunities including next-day referrals, hygiene kits, and medical education and training among others, UR Street Health is well poised to continue addressing the needs of the unsheltered homeless in the Rochester area. Our hope is that future projects will continue to develop the network of care for this population. Additionally, we perceive a need to better understand the population we serve, and feel that a formal needs assessment may improve the efficiency of our efforts.

Community Health Research

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Project THRIVE: Pilot Year Data Collection at City of Rochester Recreation Centers

Introduction: As part of the Office of Adolescent Health Teen Pregnancy Prevention (OAH TPP) Initiative, the City of Rochester is replicating the evidence-based, youth-driven service learning Teen Outreach Program™ (TOP™) for youth ages 11-14 in City of Rochester Recreation Centers (RCs). The TOP™ curriculum follows a youth development model to help teens cultivate a positive self-image, effective life management skills, and achievable goals; and has demonstrated statistically significant reductions in teen pregnancy, school suspension, and school dropout rates for participants in previous implementations. The City of Rochester aims to replicate these results by partnering with the University of Rochester to independently evaluate implementation fidelity and outcomes using a randomized control design. Randomization is cluster-based and occurs at the level of the RC, with control RCs receiving the Work Readiness program (WR), a monthly job skills and goal setting curriculum without service learning, safe sex, and youth-led discussion components. The federally funded implementation of TOP™ and WR jointly is called Project THRIVE (Teens Helping to Reinvent Identity, Values and Empowerment) and is an ongoing program in 11 RCs, slated to engage 440 youth each year for the next 3 years.

Objective: As a medical student interested in community based research, my role was as a research assistant aiding with the administration of endpoint surveys to THRIVE Participants. My additional goals were relationship building with THRIVE team members, exploration of the RC culture, familiarization with the network of agencies in Rochester dedicated to youth development and service, as well as learning about the process of community partnered research from the academic perspective. To work towards these goals I participated in meetings between THRIVE leadership and with granting bodies (OAH, TPP Initiative). I also attended a Project THRIVE conference, several breakout sessions on Youth Development, and TOP™ facilitator training to be a part of community building between the different organizations involved in THRIVE.

Background: Rochester is a community in need of public health interventions aimed at reducing teen pregnancy and STI transmission rates. The RCs participating in Project THRIVE are located in 5 of the top 13 zip codes in New York State with the highest birth rates for females ages 15-19. Additionally, in Monroe County, 2010 data indicate that 45% of new HIV cases are among persons less than 25 years of age. The proportion of newly diagnosed HIV cases occurring in persons less than 25 years of age (as a subset of all age groups) has steadily increased since 2006. The TOP™ curriculum was chosen for this intervention because of its evidence-based history with reduction of teen pregnancy, school suspension, and school dropout rates. TOP™'s effectiveness is theorized to stem from its youth-driven approach- which allows youth-led discussions of future life options, emotional and decision-making skills, relationships, and values- as well as the formation of strong intergroup relationships, with facilitators serving as adult mentors and resources. Structurally TOP™

uses weekly meetings and youth-led community service coupled with discussions about the service. Less than 10% of classroom time focuses on education about safe sex: abstinence, contraceptive use, and STI transmission and rates. Teens are primarily engaged in meaningful discussion that fosters a sense of purpose, connections, and involvement in community.

Methods: Endpoint data collection for youth participating in THRIVE programming during the 2011-2012 school year (Pilot Year) was achieved with a three-part survey instrument. Part A contained questions about demographics, school and home, risk behaviors of the youth and their friends, attitudes towards self and parent/guardians, and involvement with parent/guardians and RC staff. Part B was divided into two components, one for youth who reported having engaged in sexual activity (B1), and the other for youth who denied this (B2). Both Part Bs contained questions about future goals, sources of information, participation in RC activities, and the curriculum's service learning component (for TOP™ participants only). Part B1 additionally contained questions on sexual history, sexual behaviors, contraceptive use, and relationship history and goals; while Part B2 contained questions on attitudes toward community, school and neighborhood, participation in organized activities, perceptions of peers' risk behaviors, attitudes about sex and safety, work, and recreation. Surveys were administered during the months of June and July at the RC sites with guidance from TOP™ facilitators, WR consultants, and RC staff.

Results: Survey responses from the pilot year are currently being compiled and analyzed. A Corrective Action Plan regarding Project Year 3 (beginning now) was submitted to the OAH. Ongoing recruitment of youth in RCs, schools, and the community is being enacted by the implementation team. The groundwork for a detailed Tracking Plan to improve retention of participants for services, endpoint data collection, and future data collection was designed. Personal learning experiences abounded. There are a myriad of agencies in Rochester who work cooperatively to serve youth as a part of Project THRIVE. My newfound familiarity with these resources along with personal connections formed can facilitate future outreach projects for medical students. Complex interpersonal and inter-organizational relationships were observed, which included conflict and disconnections in communication as well as successful cooperation. Of note were three main difficulties in cooperative community research. First, the requirements of a scientifically valid experimental design are often not consistent with the practical reality of the environment in which the experiment is being conducted. This is further compounded by the second challenge of understanding differences in culture between research and community partners. Researchers aim to explain the culture of academia to community partners while community agencies also teach on their own culture. The goal is mutual understanding of the methods employed on each side of the equation so that each partner can fairly make requests of the other. Thirdly, as with any randomized control trial, it is possible that the experimental design will not provide the greatest benefit to the community as could be possible with the resources allotted. It is instead intended to test a hypothesis in a way that allows a supported conclusion to be drawn, so that in the *future* the greatest benefit can be derived. This can be a hard pill to swallow when all parties involved in the research care deeply about serving and improving the community. Respect and dignity were paramount.

Conclusion: To reiterate, some observed difficulties for community research include: conflicts between scientific rigor and practicality, communication across gaps in perspective, and divide between experimental design and greatest benefit to the community. As for further impressions, the culture of cooperation toward public health that Rochester is often credited with does indeed exist. However, there are still barriers for smoothly run community partnerships between the academic researchers, the City, and community-based organizations. Attitudes in the community that research exploits rather than promotes improvements are still present and it is my hope that successful

partnerships like THRIVE will continue to show the broader Rochester community that the first objective of community based public health research is to improve the health of the community.

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Community Health Research

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Teaching through narrative: exploring the experience of young transgender, genderqueer, and non-gender conforming individuals in clinical settings

Objectives: This project aims to address a gap in cultural competency training in medical school related to transgender identity and experience in the context of medical care.

Background: Although definitions of “transgender” vary, at the broadest level the word connotes a difference between the gender assigned at birth and an individual’s gender identity or expression. Included within the spectrum of gender identities are individuals who identify as intersex, bigendered, genderqueer, or otherwise non-gender conforming. Since gender identity data is rarely obtained in large surveys, the demographics of transgender people are not well characterized. Estimates of Gender Identity disorder as classified in the DSM-IV range from 1:30,000 natal males and 1:100,000 natal females in the United States to 1:2,900 natal males and 1:3,000 natal females in Thailand.

Even though the majority of care any LGBT person receives has little to do directly with his or her gender identity or sexual orientation, these individuals are acknowledged to have unique health needs and face acute disparities in receiving all types of healthcare. Many factors contribute to the disparate outcomes seen between transgender and cisgender patients. In provider offices, transgendered people might experience overt hostility and even denial of service. Even in the absence of this “enacted stigma,” fear of such treatment can influence healthcare-seeking behavior, as can any generalized discomfort observed in their healthcare providers.

Structural barriers such as the lack of marital benefits or insurance coverage of gender-affirming care such as hormone treatment can also negatively influence healthcare outcomes in the transgender population. Sometimes, in order to receive gender-affirming care, insurance requires a diagnosis of the psychiatric condition “gender identity disorder” (GID) which is at odds with many people’s beliefs about transgender identity. The upcoming fifth edition of *Diagnostic and Statistical Manual of Mental Disorders* will likely re-characterize GID in more

neutral terms as “gender dysphoria” (GD) with separate entries for GD in adolescents and adults and GD in children.

Even if stigma and barriers were to disappear, transgender health would still suffer from a dearth of medical research and provider training. For example, there are no studies on the long-term effects of hormone treatment received by many transgender individuals. The majority of LGBT health research has been related to sexually transmitted diseases, with lack of research of any other issues. In a recent survey of American and Canadian medical schools, a third of schools reported zero required clinical hours for LGBT content, with a median of 5 and mean of 7 hours in total. Transgender-related topics such as sex-reassignment surgery and transitioning were the least-taught topics among the 16 surveyed, with less than 40% of medical schools teaching any material on the subject. Even at University of Rochester, the afternoon lecture and small group session devoted to sexual orientation and health in the first year curriculum has had to modify content to leave out transgender health for lack of time available to address the subject.

Methods: Interviews were conducted to explore the range of experiences and emotions associated with seeking medical care as a transgender or genderqueer person. Areas of discussion included particularly positive or negative interactions with medical professionals, ways that offices can make transgender patients feel welcome and comfortable, and what are the areas of greatest concern as viewed by members of the transgender community.

Results: The experiences of transgender individuals varied dramatically with regards to medical provider conduct, training, and office setting. An FTM man reported a physician abandoning him in the exam room after he informed the doctor of his gender identity and disclosed he had intact breasts, prior to a lung auscultation for suspected pneumonia. On the other extreme were stories about doctors who were welcoming, non-judgmental, and if not initially knowledgeable about transgender health care, were open to learning from their patients and from other resources.

Conclusion: In terms of what offices can do to be welcoming, respondents suggested having an option to indicate gender/preferred name/pronouns on intake forms, prominent "safe place" signage, and the availability of gender-neutral bathrooms. However, the most important issue noted by nearly all interview subjects was the cost of obtaining gender-affirming care, regardless of insurance status. Although some advocacy by physicians can be helpful in obtaining approval for specific procedures for their insured patients, many policies directly forbid coverage of gender-affirming medications and procedures. In cases of uninsured patients, there is little individual physicians can do to reduce the cost of medications and procedures. However, doctors can still help in many ways, such as by lobbying lawmakers and insurance companies in concert with transgender rights organizations, or by volunteering in clinics designed to be inclusive towards transgender patients.

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Community Health Research

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Grassroot Rochester - ESL Pilot Program

Introduction: With the support of Grassroot Rochester, an ESL pilot project was initiated. The aim is to use soccer as an after-school incentive for students and supplement their ESL curriculum.

Objective: To develop a self sustained ESL program and strengthen our ties with Rochester's ESL educators, in order to improve the overall academic performance of ESL students.

Background: According to the New York State Education department, high school graduation rates statewide continue to rise slowly over time. Last years data indicates a 73.4% four year high school graduation rate, compared to the previous cohort where 71.8% graduated within four years. Unfortunately, Rochester's graduation rate of 46.1% is markedly lower than the New York State average. Equally as significant is the standardized measure employed by the Board of Regents. This board utilizes data from Math and English regents scores to predict future success of high school graduates. While 50% of white students met the college-ready standard, the same was true of less than 15% of minorities. This wide gap observed can be attributed to various factors, including the fact that many minorities adopt English as their second language.

Studies have demonstrated after school programs across the country, to be highly effective in achieving their goals of improving the overall tests scores and graduation rates. Grassroot Soccer and Starfinder, are sports for development models, that have been successful in increasing HIV awareness and improving ESL test scores respectively.

Methods: Literary reviews and internet sources were utilized to gain information on Education in Monroe County, Starfinder, Grassroot Soccer, and other sports for development models.

Results: Grant proposals will be submitted to the Center for Community Health at URMC.

Conclusions: The current grant proposal will provide a platform to seek further funding opportunities, allowing Grassroot Rochester to establish an ongoing ESL program, and expand the number of schools benefiting from this program.

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Community Health Research

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Reproductive Health Externship

Introduction: Medical Students for Choice (MS4C) ® is a non-profit organization within the United States that works to support and increase healthcare abortion providers. MS4C was developed in 1994 in response to the “graying” of current abortion providers as well as the increase in violence against abortion care providers. MS4C major mission is to increase activism and grassroots support among medical students, residents, and physicians. Also, MS4C works to integrate abortion education and training into medical school and residency curricula. As part of this mission, they provide resources for students like me to perform and complete abortion training during their medical school career.

Objective: I worked within a supportive environment at URMC's Women's Health Clinic to learn the technical skills necessary to complete first and second trimester abortions. Also, I began to develop the compassion and interpersonal skills necessary to help women in this stressful and emotional decision making time.

Background: In the United States, 51% of pregnancies are unintended (1). Of this 51%, 43% will result in the termination of the pregnancy (1). When compared to other developed countries, the US has a disproportionately high unintended pregnancy rate. It is important to understand that regardless of the legality of abortion services, women will resort to induced abortion. The highest abortion rates exist in countries where there are the most restrictive abortion laws, such as Latin America, Africa and the Caribbean (2). Worldwide, 20 million abortions are performed in unsafe conditions (2). In order to provide comprehensive, safe women's healthcare across the country, abortion education and provision needs to be an integral part of physician training and practice.

Methods: I worked with two family planning physicians and a nurse practitioner to provide first and second trimester abortions to women throughout Western New York. Our practice is the only clinic that provides second trimester abortions for Medicaid patients, besides NYC. I began learning the art of taking a complete and succinct history and physical, geared towards obstetrics and gynecology. As my skills developed, I worked on options and contraception counseling. Within the clinic, a large portion of the time spent with the patients was educating patient on contraception options. Shortly after, I began to develop in-office procedural skills, such as speculum exams, culture analysis and laminaria placement for our second trimester patients. Further into my training, I learned how to complete first trimester abortions using MVA's with patients under moderate sedation. Also, I assisted and performed second trimester abortions in the operating room with the patients under general anesthesia. Throughout my externship, I shadowed physicians and other providers at Planned Parenthood in their clinic and OBGYN providers in the Labor and Delivery unit at SMH.

Results: During my summer externship, I learned a comprehensive approach to abortion care. Not only did I learn how to complete first and second trimester terminations, but I learned invaluable clinical skills. I developed the ability to provide option counseling and proper patient consent. I researched information on contraception which allows me to properly provide contraception counseling. Finally, I develop critical intrapersonal skills necessary to make our patients comfortable and respected during a highly stressful time.

Conclusion: MS4C Summer Externship's mission is to provide opportunities for students to learn essential healthcare skills that may not be taught at other points in their education. I learned critical skills for comprehensive women's health and developed the potential to teach other peers and providers the importance of abortion training in the American healthcare system.

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Community Health Research

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Future Doctors and Underserved Patients: A Mutually Beneficial Relationship

In the last ten years, student-run free clinics have developed throughout the United States to help serve uninsured and underinsured patients in the community. A few years ago students attending the University of Rochester School of Medicine developed their own local clinic called URWell. This clinic specifically provides essential care to the indigent population of Rochester, NY. The clinic is run from two separate locations, Asbury First Methodist Church and St. Joseph's Neighborhood Center. The latter is a daytime run clinic that URWell volunteers extend into Tuesday evenings. This site hopes to provide people, who otherwise would not have access to the health care system, with a primary care provider. Asbury, which is run each Thursday night, is not directly connected to a clinic like St. Joseph's, but was recently started by medical students, utilizing space in the Asbury First Methodist Church building. Asbury focuses on acute care and therefore is not a substitute to primary care. Both sites are a vital resource to those who would not otherwise have access to health care.

Each summer, several rising second year medical students from the University of Rochester School of Medicine and Dentistry have the opportunity to participate in the URWell Summer Internship Program. In this role, the students' central purpose is to maintain a strong relationship between the medical school and the two community organizations, St. Joseph's Neighborhood Center and Asbury First Methodist Church. For 8-10 weeks the students volunteer their time at St. Joseph's Neighborhood Center, assisting with administrative needs along with addressing opportunities for improvement identified by the senior staff. In addition to working regular hours at St. Joseph's Neighborhood center during the day, the students function as administrative coordinators at the weekly URWell clinics. Finally, during the summer internship, the students have the freedom to develop their own unique projects aimed at improving URWell.

URWell Summer Interns from past years have developed a wide variety of projects invaluable to the URWell clinics at both sites. Projects generally aim to improve clinic efficiency, further health care access to the community, improve medical student involvement and learning, or research unique aspects of the patient population. This year, the URWell Summer Interns focused on topics such as diabetes prevention, new student training, and a chart review focused on dyslipidemia.

The Diabetes Prevention Program is a recent large-scale NIH study demonstrating the delay and prevention of diabetes. This study showed that pre-diabetic individuals who lose 7% of their current weight through healthy eating, and do 150 minutes of brisk physical activity each week will decrease the risk of developing diabetes by more than half. The University of Pittsburgh implemented the results of the study into The Group Lifestyle Balance Program. This program will be implemented

into our clinic with weekly classes that we will encourage pre-diabetic patients to attend with the aim of preventing diabetes in those we serve.

A retrospective chart review of patient data will be performed assessing quality of care surrounding dyslipidemia. The chart review was focused on screening, diagnosis, and treatment of dyslipidemia. According to The Third Report of the National Cholesterol Education Program Expert panel on Detection, Evaluation, and Treatment of High Blood Cholesterol in Adults (Adult Treatment Panel III, ATP III) the treatment of dyslipidemia as a risk factor for coronary heart disease requires a vast amount of information about any given patient. Many roadblocks were encountered with this study including poor chart documentation, patients lost to follow up, and most critically the lack of adoption of a chronic care model. From the data gathered in this study, the URWell teams at St. Joseph's Neighborhood Center can see the focus needs to be changed to a chronic care model so we can adequately screen our patients for dyslipidemia.

These projects will lead to students that are trained more consistently, patients will be provided with additional prevention services, and a focus on a chronic care model at the St. Joseph's Neighborhood Center. Future students will be able to continue these projects at URWell improving the quality of care for the underinsured patient population of Rochester.

Community Health Research

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Research Title: Grassroot Rochester – HIV Prevention Through Soccer

Introduction: This summer experience provided support to Grassroot Rochester, a growing University of Rochester student-run organization which aims to reduce HIV risk among area youth through a unique soccer-based education model.

Objective: To develop a proposal framework to build community-URMC partnerships for the reduction of HIV risk among Monroe County youth using the Grassroot Soccer model.

Background: In Monroe County, NY, an alarming rise in the proportion of new HIV cases was observed among adolescents and young adults under 25 in 2010 (45% of new cases, versus 14% in 2007). These data highlight the need for earlier, more effective HIV prevention efforts, particularly among youth.

Current educational policy in the state mandates an age-appropriate HIV/AIDS curriculum delivered over 5 to 6 lessons throughout the school year. However, the above numbers and results from the Youth Risk Behavior Survey published by Monroe County Department of Public Health suggest that youth could benefit from additional HIV education which complements the state-mandated approach. The Grassroot Soccer model has been shown to be highly effective in increasing HIV knowledge, raising awareness about HIV/AIDS community resources, and changing negative attitudes toward HIV around the world.

Methods: Internet searches and literature reviews were conducted on HIV/AIDS demographics in Monroe County, NY; HIV education; and the Grassroot Soccer model. Key informant interviews were also conducted with University of Rochester faculty and community partners.

Results: A grant proposal was developed and submitted to The Greater Rochester Health Foundation for the 2013 Opportunity Grant.

Conclusion: Opportunity Grant awards will be announced in January 2013; regardless of the outcome of this funding cycle, the proposal framework developed this summer will allow Grassroot Rochester to continue to seek funding to further community partnerships and empower Rochester youth in the fight against HIV/AIDS.

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International Medicine Research

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Shared Decision Making: An Argentine Narrative

Background and Introduction: Medical professionals need to better understand shared decision-making (SDM) surrounding illness in order to ensure that the patient's wishes are respected. SDM is an approach to care that takes into account, and acknowledges differences within, the goals of the patient, family, and doctor when deciding on a course of action (or inaction). The communication between medical professionals, patients, and patients' families must be better understood to facilitate consensual decisions, especially near the end of life. By observing how clinical decisions are made from a foreign perspective, this type of research has the potential to provide new insight and improve my understanding of decision-making in the United States.

Objective: My objective was to record thirty individual stories that exemplify how decision making is shared and divided in medical interventions in Mendoza, Argentina. The purpose of this narrative study was to discover who makes decisions in each case and how those decisions are shared. I seek to understand the lived experiences of all parties involved in (or excluded from) these healthcare decisions.

Methods and Findings: Using six standard questions as a starting point, I recorded stories and experiences from the perspective of 13 healthcare professionals, 6 family members and 8 patients. I collected individuals' stories about specific medical interventions in 10 different cases. I attempted to approach this issue from multiple perspectives in order to gain some understanding from each person about whom or what influenced a particular care decision. I asked specific questions about how medical care or treatment was proposed, and how the respondents felt about the power dynamics involved in the decision.

Conclusion: There were widely varying accounts and opinions for each clinical case. However, some themes shine through. The perception of how much each decision is shared correlates roughly with how much decision making power each individual has. Thus in general, the attending physicians perceive the decisions to be shared equally, the residents a little less so, and patients' opinions vary. In one case, the attending stated clearly that the patient has the final say in every decision while the patient stated that she was willing to do whatever the doctors thought was best. In another the resident stated that there were three reasonable treatment

options while the patient reported that there was only one treatment option available. Moving forward in my own medical career, I will keep these apparent contradictions in mind and encourage my colleagues and patients to think about not only what decisions are being made, but also about how each decision is made.

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International Medicine Research

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An Evaluation of the Potential For Collaboration Between Western Medicine and *Rongoā* Maori Traditional Healing in Te Tairawhiti (Northeastern New Zealand)

Introduction: This is an interview-based qualitative study conducted to learn about attitudes towards Maori traditional healing within the patient population of Ngati Porou Hauora.

Objective: To evaluate local patient attitudes in rural, northeastern New Zealand regarding rongoā Maori (RM), and the potential for its integration into conventional medical practice in the primary care setting. The results of this research will be combined with workshops, literature review, and other data sources to advise case study design for a larger report to be produced by Te Haerenga o Te Tairawhiti (THoTT).

Background: RM refers to the diverse healing methods embedded within traditional Maori culture, and includes herbal preparations, massage-based therapy, water/seawater healing, prayer/spirit channeling, the healing property of the Maori language itself, and other forms. It is based on the idea that the island's natural world has always provided—and will continue to provide—curative tools to the Maori people. It emphasizes a holistic view of health, in which a person's wellbeing is not limited only to the physical, but also to emotional, spiritual, familial, and even land-based levels of health. RM is the current remnant form of the continuum of Maori healing, which far pre-dates the colonization of New Zealand by Europeans. From the start of colonization in the 19th century and well into the mid-20th century, rongoa Maori, along with other aspects of Maori language and culture,

was highly suppressed by the Western-dominated majority of New Zealand. However, the past few decades have witnessed a resurgence of Maori culture and language in the New Zealand public, and many see the respect and use of RM to be an essential feature of this movement. In other developed nations, clinicians of conventional medicine are being forced or compelled to learn more about complementary and alternative medicines, since many patient populations are taking advantage of these services and therefore represent an aspect of their total health maintenance. Meanwhile, in nations where both conventional medicine and traditional healing cultures coexist such as China, South Africa, and India, precedents have been made in the integration and cooperation of these disciplines in ways that may potentiate the development of similar models in New Zealand. While multiple national organizations of RM healers have temporarily assembled in the past, the first fully cohesive national organization (Te Kāhui Tāwharautanga ō Ngā Rongoā), has recently formed and is in its early stages of structural and organizational development. Similar research to this one is being conducted in other regions and at a national level, but this study by THoTT is the first to look closely at RM attitudes and practice in the rural Tairāwhiti region.

Methods: Preliminary, informal informational gathering occurred through various meetings and encounters with local clinicians (doctors, nurses, mental health professionals, etc.), as well as healers, patients, and community members. An extensive literature review was also carried out in which key obstacles and themes were identified from integrative care models for complementary, alternative, and traditional medicines in other countries. The knowledge gained from these sources advised the drafting of interview questions. The patient interviews were carried out on a series of clinic days at Ngati Porou Hauora's hospital in Te Puia Springs, called Te Whare Hauora o Ngati Porou. Small revisions to the questions were made after each day of interviews. The final seven interviews were transcribed and analyzed qualitatively using a coding technique, in an attempt to identify, categorize, and stratify themes discussed by patients.

Results: The interview participant sample included patients with varying levels of comfort and knowledge regarding the utilization of RM, ranging from major support to total avoidance. Among patients who were in favor of RM, all had been influenced by family exposure early in life. Conversely, those who were least interested in utilizing RM did not have exposure to it during childhood. Regardless of opinions surrounding RM integration, participants volunteered a link between whether or not they practiced RM, and the suppression of Maori language and culture during the mid-20th century. When initially asked about RM, all participants initially discussed treatments under the category of "rongoa rakau", the plant-based remedies. When clarification was made to include other aspects, many participants responded to the mention of mirimiri (the massage aspect of RM), and even those who were averted to rongoa rakau use were open to the use of mirimiri. Many participants recalled the presence of mirimiri use in the hospital in earlier years. The receiving of and exposure to mirimiri tended to be much less family-based than rongoa rakau, and much more heavily based on a non-familial community of mirimiri practitioners. The participants often related the idea of integrative medicine to a general desire to receive more holistic and biopsychosocial care. This included aspects of care like the manner of conversation between doctor and patient, the permitting of family presence around the sick patient during healing, the culturally sensitive disposal of surgical specimens, and the incorporation of lifestyle modification into a treatment plan. Some of the favor towards RM use appeared to be derived from negative sentiments regarding artificial drugs, and a preference for treatments perceived by the patient as "natural" (being found in the natural world, and requiring little artificial synthesis or modification). Despite some expression of preferences and suggested adjustments to patient care methods, many patients expressed a deep level of trust in their clinicians. In fact, four participants expressed a particularly extreme trust in doctors, including references to "faith" or a "leap of faith", and also other

descriptions of strong, unquestioning dependence on the doctors' decision-making. Three of the participants brought up personal RM experiences outside of the area, in more populous urban centers of New Zealand. These participants who had left the rural east coast, spent time in a more populous area consistently had more experience with professional RM healers (non-relatives) and had more developed thoughts on the issues before entering the interview, when compared to other participants.

Conclusion: The main lesson to be learned from this preliminary exploratory qualitative research is that the Ngati Porou Hauora patient population appears to be diverse in its level of adherence to Maori tradition, including but not limited to its experience with RM. Therefore, in proposing a future model of RM integration, one must not make assumptions about wishes of the community based on ethnic heritage alone. Based on the data and precedents abroad, the mirimiri aspect of RM could potentially serve as a trial integrated service, which could then blaze a trail for an infrastructure to later support other RM services. The discussion of the primary issue of RM integration into primary care elicited broader themes regarding the way patients perceive illness and make decisions about their health. Based on this knowledge, there appear to be opportunities for local clinicians to learn more from engagement with their community and patient population. Based on these interviews, local patients seem to rely on the trust and expertise of their general practitioners. This may hold importance to the role of GPs as future gatekeepers who connect patients to integrative care services. Moving forward, all stakeholders in Maori health must think carefully about the role of RM in an effective 21st century approach to the self-determination of the Maori people.

International Medicine Research

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Development of a Questionnaire to access the well-being of Ethiopian patients after corrective spinal surgery

Background: In Ethiopia, spinal deformities pose a severe problem in the country because the prevalence is unknown and there is a lack of specialists that can treat this condition. The main causes of these deformities include idiopathic scoliosis, tuberculosis kyphosis, congenital and neuromuscular kypho-scoliosis.

Introduction: Dr. Richard Hodes serves as the only spine specialist in Addis Ababa, Ethiopia and aids thousands of poor patients by referring them to Ghana to receive spine surgery. To our knowledge, there is no culturally competent questionnaire available to compare the physical and social well-being of Ethiopian patients post-operatively.

Objective: This study serves to develop a reproducible questionnaire that will access patients' health post-operatively in order to analyze the patients' physiological, social, and economic state associated with corrective surgery for spinal deformities.

Methods: The development of the questionnaire included creating retrospective interview questions informed by literature review and questions selected from SFS-36 and SRS-22. Dr. Hodes and assisting physician, Dr. Teferdegn added additional questions. The survey was translated into Amharic, the local language and then administered to patients for suggested modifications.

Results: The survey is designed to be given 6 months or more following surgery. It has 29 questions and takes an average of 23 minutes to complete. Six domains were created and topics include general health, limitation of activities, work/other daily activities, pain, emotions, sleeping discomfort, and neurologic function. Responses were multiple choice with one opened ended question that addressed comments and concerns of the patients medical care by the Dr. Hodes and his team.

Conclusion: This survey takes language and culture into consideration while including questions that assess patients' wellbeing, psychological and functional states, neurological ability, and emotional feelings. The patients were able to confidentially select a multiple choice answer that described their well-being and physical ability. The information from this study can be used to establish a structured

follow-up system that effectively assesses the well-being of the patients seen by Dr. Richard Hodes 6-months after corrective spine surgery.

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International Medicine Research

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Patterns of CAM Usage and Health Literacy among cancer patients in India

Introduction: The purpose of our project is to gain a better understanding of complementary and alternative medicine (CAM) in India, where CAM practices are closely intertwined with the nation's history and are regularly used in conjunction with allopathic medicine. Additionally, we would like to understand the rationale behind CAM usage by various patients and gain some insight into their level of health literacy.

Objectives: The project was designed to address the following goals:

- Determine the frequency of CAM usage among cancer patients in India.
- Determine if there is any correlation between demographic factors and frequency of CAM usage.
- Explore the various reasons for CAM usage (patient decision-making).
- Explore patient access to health care and subjectively assess health literacy based on access to health care, sources of health information, and notable gaps in health literacy.

Background: The practice of Complementary and Alternative Medicine (CAM) is on the rise in the United States. Approximately 38 percent of adults and 12 percent of children are using some form of CAM, up from 36 percent of adults in 2002 (Barnes et. al, 2008). These CAM practices are used in an attempt to seek a more holistic approach to disease management, pain and stress relief, and to address non-physical issues associated with many illnesses (Richardson et. al, 2000).

CAM practices are an integral part of Indian culture; traditions such as Ayurveda and Yoga have by far the most widespread usage (Broom et. al, 2009) and are used by close to 80% of the Indian population (Brown, 2009). Understanding the place of medical interventions in countries whose cultures are heavily tied to religious healing and alternative medicine has important implications in terms of health literacy.

Methods: Subjects, who spoke English, Gujarati, and Hindi were recruited from Vedanta Institute of Medical Sciences in Ahmedabad, Gujarat, India. All surveys were administered verbally. Researchers spoke to family members who were present at the the time of the appointment to complete the survey. The study survey addressed the following topics: demographics, type of cancer and treatment, the type of alternative medicine subjects had/were using, and sources of health information.

Results: We recruited 180 subjects, ranging from ages 18-79. Most of the subjects were receiving treatment at Vedanta clinic for breast cancer (25%), lung cancer (16%), gastrointestinal cancer (13%), and lymphoma (13%). Frequency analysis indicated 85% of our subjects used some type of complementary and alternative medicine practice; this dropped to 65% when prayer was excluded. Prayer was excluded from the data analysis due to its strong integration into daily Indian culture. The top four types of CAM practices, excluding prayer, were nutrition and diet changes (46.7%), Ayurveda (27%), Astrology (12%), and Yoga (10%). Subjects also used home remedies such as Wheat Grass, Aloe Vera, Cow Urine, Neem Seema Khaneja, MD, Adjunct professor, University of Rochester Medical Center, powder, Turmeric, Dates, and Alfalfa. The high frequency of nutrition and diet changes were due to doctor recommendations in an attempt to prevent side effects of chemotherapy and hygiene.

Data analysis indicated that there was no clinically significant difference between CAM usage and gender, as both males and females seemed to practice CAM equally (49.16 vs. 50.84, respectively). There appeared to be a statistically significant higher frequency of CAM usage amongst older subjects, ages 50-79, when compared to the 18-49 age group (63.64% use vs. 36.36%) and amongst those who were highly educated [college (60.53% use vs. 39.47%) and graduate degrees (68.09% use vs. 31.91%)].

Most subjects received their general health information from doctors (49.4%), family members in the medical profession (14.3%), Internet (12.0%), newspapers (10.4%), and TV (8.5%). Furthermore, the majority of subjects reported finding their oncologist via referrals (61.7%) and through family and friend recommendations (31.4%). Subjects wanted more information primarily about the treatment such as drug side effects and treatment course, information about cancer (how/why it occurs, relapses and metastasizes), and payment options (availability of government subsidy).

Conclusion: Our findings of CAM usage amongst cancer patients in India were similar to the usage amongst US patients, such that older and highly educated patients were more likely to use CAM. However, there was no significant difference between gender usage in India as opposed to the US, where females were more likely to use CAM than males. There was a higher percentage (85%, 65% excluding prayer) of cancer patients using alternative medicine in our study, as opposed to 40% in western society.

We found a high rate (67.6%) of self-pay as opposed to insurance coverage (29.6%), reflecting lack of subsidized healthcare. Patients had the option to enroll in clinical trials, which provided partial or full subsidies for treatment. Patients refrained from disclosing their CAM usage to doctors out of respect, and due to stigmas against CAM use in the medical field.

Our definition of alternative medicine, as defined by the options we listed on our survey, did not match that of our subject pool. There were certain remedies (i.e. use of aloe vera, cow urine, neem powder) that were not disclosed by the subjects until they were explicitly asked if they used these products. Subjects also demonstrated limited knowledge about the concurrent use of alternative and allopathic medicine.

International Medicine Research

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The Impact of Health Knowledge on Disease Perception and Preventative Behaviors in Rural Malawi

Introduction: The Republic of Malawi is a densely populated, land-locked country in sub-Saharan Africa with a substantial burden of disease. Life expectancy in 2010 is 51 years, with malaria and HIV/AIDS accounting for the majority of disease and mortality. High rates of cholera, tuberculosis, and mental illness also contribute to the low life expectancy (1).

In the past decade, initiatives such as the distribution of free bed nets were introduced in Malawi to reduce disease incidence. While the focus of these projects has been on implementing preventive measures and educating the community about different diseases, less emphasis has been placed on understanding the local perception of disease. Disease, an abnormal physiological function, is distinguished from illness, an individual's perception and experience of being sick (2). Illness is culturally influenced, and is often important in determining a patient's attitudes and behaviors towards disease prevention (2). Therefore, a comprehensive understanding of illness within the Malawian population is a critical component of improving healthcare.

In Gowa Mission, health educators may be in a position to influence local residents' understanding of illness and prevention through their role in teaching about health and disease. An understanding of educators' own disease knowledge and perception, in the context of their work responsibilities and access to resources, may provide insight into the factors that impact the success of preventive strategies such as chlorination of drinking water, bed nets, and condoms.

Objective: The purpose of the project was to evaluate the local knowledge and perception of malaria, cholera, tuberculosis, HIV/AIDS and mental illness among community health educators in Gowa Mission. The overall goal was to identify factors that influence the local residents' understanding of these five diseases.

Background: Gowa Mission is an epicenter for 26 surrounding villages in the Ntcheu District of southwest Malawi. The mission includes schools, churches, a police outpost, and the only health clinic within an area of 20 kilometers. Prior research conducted by University of Rochester School of Medicine and Dentistry (URSMD) students identified diseases that residents of Gowa Mission considered relevant to their health. In the subsequent year, URSMD students assessed the knowledge

and perception of five of the relevant diseases (malaria, cholera, tuberculosis, HIV/AIDS, and mental illness) amongst local residents. The data indicated that local residents most commonly use the health clinic, radio, and mobile clinics to obtain their health information.

Methods: Research subjects were recruited and enrolled between May 29, 2012 and July 5, 2012 in Gowa Mission. Semi-structured interviews were conducted in the homes and/or workplaces of key informants. The interviews were conducted in Chichewa through a translator, or, if the research subject was fluent in English, by the co-investigators. The purpose of the study was explained to the study participants, and their informed consent was verbally obtained.

Survey questions were translated into Chichewa, the national language of Malawi, and then back-translated by a different interpreter. The survey was piloted with community members prior to finalization. Data was hand-written using a standardized form, and stored in a secure location on-site. De-identified data was transferred to a computer database upon return to the US.

Results: 14 Gowa community health educators were interviewed. On the knowledge test, 100% (n=14) answered the 7 questions about HIV/AIDS correctly. 21% (n=3) answered the question about cholera seasonality incorrectly. The most questions answered incorrectly were those about mental illness, with 36% (n=5), 14% (n=2), and 7% (n=1) incorrectly answering questions about treatment, susceptibility, and transmission, respectively.

Data from the seasonality and co-variation calendar indicate that malaria and cholera incidence was perceived to be the greatest during the rainy season (October to April), with increased education of these two diseases beginning in September and ending around March. Tuberculosis and mental illness cases were thought to be more prevalent during the dry season (May to October). The months perceived to have the greatest TB or mental illness education varied. 21% (n=3) perceived TB education to occur from January to December with no month of increased counseling. 29% (n=4) perceived the education of mental illnesses to be rare or nonexistent. 71% (n=10) and 64% (n=9) perceived HIV/AIDS to be contracted and educated on, respectively, at a stable rate throughout the year. For 57% (n=8) of subjects, their perception of the months of the rainy season overlapped with the months that they perceived to have the highest number of people in the community “most busy” working and the highest food shortages in the community.

Of the five diseases, HIV/AIDS was perceived to be the most severe and burdensome, while malaria was perceived to be the most frequent. This is in contrast to data obtained from previous interviews with Gowa community members who perceived HIV/AIDS as the most severe, and perceived malaria as the most frequent and burdensome. HIV/AIDS and malaria funding for prevention and educational resources was believed to be the greatest, although both diseases were still felt to need more attention from the government and NGOs. In particular, HIV/AIDS testing kits were often noted as a necessity that was often lacking. In contrast, mental illness received the least, if any, funding for resources. The community’s primary sources for health information were perceived to be the health clinics, mobile clinics, radio and school, with malaria and HIV/AIDS being the most discussed diseases.

Conclusion: The greatest gaps in knowledge were in understanding disease treatment and susceptibility, and disease transmission and prevention among health educators and local residents, respectively (3). Educators and local residents concurred in their perception of INTERNATIONAL
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HIV/AIDS as the most severe, and malaria as the most frequent of the 5 diseases. The reason for this incongruity is unclear, but may be related to the funding for prevention and education of these diseases. The disparity in disease knowledge and attitudes among local residents and health educators may be influenced by their individual and occupational experiences with the diseases.

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International Medicine Research

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Medical Student Attitudes toward Complementary and

Alternative Medicine in Cusco, Peru

Introduction: The use of complementary and alternative medicine (CAM) is becoming increasingly common in the United States. In 1993, a national survey found that one out of every three adults in the United States used at least one complementary or alternative therapy¹. More recently, the Centers for Disease Control and Prevention's National Center for Health Statistics found that of 31,044 adults surveyed, 62% had used some form of CAM in the past year.² The significant increase in CAM usage in the general population has prompted medical schools to consider its inclusion in their curricula.³ The use of CAM has also increased in Peru, although how this has affected medical school curricula is not well defined.⁴

Objectives: This study aims to quantitatively describe opinions of medical students towards complementary and alternative medicine (CAM) in the curriculum and in practice at Universidad Nacional de San Antonio Abad del Cusco, a main medical school in Peru.

Background: Cusco, Peru is situated in the Peruvian Andes in the southeast region of the country and has over 400,000 inhabitants. The native language of the Incans was Quechua, which is still spoken widely in Cusco to this day, exemplifying the continual presence of the indigenous population in modern culture. Included within this culture are strong beliefs in alternative forms of medicine. Although CAM is prominent in rural areas, its use has been on the increase in urban areas of Peru. This may create a barrier of cultural understanding between the indigenous populations and the health care system since traditional beliefs may be disregarded by current health professionals. Therefore, there is a need for better understanding between native customs and current health care practices. Medical curricula in Peru are addressing this aspect of medical care. In Cusco, Universidad Nacional de San Antonio Abad del Cusco has a required 18 week course for fourth year medical students entitled "Traditional Medicine".

Methods: The survey was in Spanish and distributed to medical students from years 1 through 6 in the classrooms prior to lecture, who had 15 minutes to complete the survey.

Results: We received responses from 51 people, 24 women and 27 men, with an age range of 16-27. Overall, 78.4% of individuals believe that clinical care should integrate the best of conventional and CAM practices. Massage therapy, nutritional supplements, and medicinal herbs were considered to

be the most effective forms of CAM and participants desired the most information about acupuncture, medicinal herbs, and nutritional supplements. 84% of participants or their family members have used some form of CAM, with the most commonly used form being medicinal herbs and nutritional supplements. There was no statistically significant difference between those students who have taken the CAM course and those who have not in their views on whether clinical care should integrate the best of CAM and conventional medicine or their desire to have CAM practice available to their patients.

Conclusion: We wanted to determine the viewpoint of students in medical school on CAM and found that the overwhelming majority did want to integrate CAM and conventional medicine in their practice. However, the traditional medicine course that is currently offered at the school is only theory-based; students do not gain knowledge about how to perform traditional techniques, which may partially explain their desire to learn more. Many students have also had family members utilize these techniques for various ailments, which may have influenced their viewpoints. Students also varied in which specific modalities they wanted training on and their results may be indicative of previous exposure or popularity of these modalities in society. In conclusion, the majority of students were in favor of the integration of CAM and conventional medicine, but more research needs to be performed in order to determine a proper integration plan in current curricula.

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International Medicine Research

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Barriers for uptake of referral services within LV Prasad's ICARE pyramid: A study at Nava Bharat Eye Centre, Khammam District, Andhra Pradesh, India

Introduction: In February, 1999 the World Health Organization launched VISION 2020: The Right to Sight – a global initiative for the elimination of avoidable blindness¹. Across the globe it is estimated that 39 million people are blind and an excess of 285 million people have severe visual impairment². Without intervention, these rates are forecasted to double by the year 2020 due to population growth and aging of the current population. For over two thirds of these people, we have the knowledge and technology to make a difference in their escapable visual disabilities.

The LV Prasad Eye Institute (LVPEI) opened in 1987 and over the last 25 years it has grown from a single center in Hyderabad to 105 centers across the Indian state of Andhra Pradesh. The International Centre for the Advancement of Rural Eye care (ICARE) is a branch of LVPEI that established the Pyramid of Eye Care with the aim of reaching all communities in Andhra Pradesh through a hierarchy of care facilities: vision centers serve the primary health needs of each community, secondary care centers serve a population close to 500,000 and provide basic surgical procedures, and, finally, tertiary care centers in the larger cities serve over 5 million inhabitants and provide the most comprehensive range of services. Over 50% of services at LVPEI are provided free of charge, irrespective of the complexity, and the same doctors and facilities are used to treat paying and non-paying patients.

Objective: The aim of this study is to assess barriers for uptake of referral services from the Nava Bharat Eye Centre (NBEC), a secondary care center, to tertiary care centers in Hyderabad and Vijayawada. The study tools are targeted at understanding the characteristic differences between those who availed referral services and those who did not avail referral services. Through this we hope to elucidate risk factors for defaulting on referral services and identify modifiable barriers that can be addressed to improve compliance with referrals.

Background: In February, 2011 LVPEI opened its ninth secondary care center in the Khammam district of Andhra Pradesh with online medical records at the main facility and its nine associated vision centers. In the year from April, 2011 to March, 2012 over 20,000 patients were seen and close to 2,000 surgeries were performed, while 1,014 cases were referred to tertiary care centers for further treatment and management.

A number of studies have been conducted to evaluate barriers within primary stages of eye care delivery in Southern India, most frequently related to the uptake of cataract services.^{3,4,5,6} At present, there are no studies that address barriers further up the pyramid of eye care, with patients who previously utilized ophthalmic services and only later failed to follow through with referrals to more

1 Reasons for which the subject was referred to tertiary centre include: Further imaging (e.g. B-Scan, MRI, FFA, OCT), the procedure is not available at Nava Bharat Eye Centre, and the opinion of a specialist is required. More than one reason may be included for a given subject.

2 Subjects were asked if they knew about the specific problem for which they were referred.

3 The average number of visits the subjects have made to Nava Bharat Eye Centre since opening in February, 2011.

4 Subjects who

Table 3. Barriers to Uptake of Referral Services

Defaulting (n=24)	Hyd - 58% Vij - 38%	54% (n=13)	38% (n=9)	25% (n=6)	71% (n=17)	1.38	4% (n=1)	4% (n=1)
Non- Defaulting (n=24)	Hyd - 71% Vij - 29%	50% (n=12)	50% (n=12)	38% (n=9)	92% (n=22)	3.75	42% (n=10)	38% (n=9)

	Personal Barriers ¹			Medical Barriers ²		Institutional Barriers ³
	Economic	Logistical	Social	Other problems	Vn Okav	
Defaulting (n=24)	54% (n=13)	29% (n=7)	21% (n=5)	13% (n=3)	13% (n=3)	21% (n=5)

¹ Barriers related to the personal circumstances of the referred subject. Economic barriers include the cost of transportation and, for paying patients, the cost of procedures. Logistical barriers include lack of escort and uncertainty about the location and how to reach the tertiary center. Social barriers include no time for travel and other family members not interested in the subject traveling for further care.

² Medical barriers are the result of other health problems preventing travel to tertiary centers, or the specific ophthalmic problem not affecting vision enough to motivate the subject to avail services.

³ Institutional barriers are problems specific to LVPEI, either from prior negative experiences with LVPEI hospitals or problems in facilitating access to referred care.

Conclusion: The largest barrier to accessing referral services is the cost of transportation as well as, for paying subjects, the procedural cost (54%, n=13). Seven of the twenty-four defaulting respondents traveled to institutions other than LVPEI following referral, and this subset should be considered compliant in accessing services. For paying subjects that cite procedural cost as a barrier to accessing tertiary services (n=9), consulting physicians should discuss the option of changing their payment status to non-paying to make treatment free and, thus, more accessible.

Some of the logistical barriers may be overcome through a brief discussion with the patient at the time of referral: how will they travel to the tertiary center? who will accompany them? do they know the easiest way to get to the center? This discussion should include any accompanying family or friends who traveled with the patient to the secondary center. While lack of escort cannot be simply overcome, addressing other logistical questions may relieve a part of the burden placed on a referred patient and their family. Medical barriers cannot be easily addressed, and it will take no small effort

to convince a patient with adequate vision that he needs to invest the time and money to travel to another city for further care. Among the five subjects who cited institutional barriers, these problems included time of response from LVPEI and dissatisfaction with the outcome of previous care.

Income is the only demographic factor that differentiates the two groups, with the families of non-defaulting subjects earning, on average, about 3,500 INR more each month. However, there are families of defaulting subjects that earn more than INR 25,000 and, conversely, families of non-defaulting subjects that earn less than INR 5,000, so income alone cannot be used as an indicator of a subject's likelihood to access tertiary level care.

On average, non-defaulting subjects visited NBEC more frequently than defaulters, even after receiving care at LVPEI's tertiary centers. The non-defaulting group also had more subjects who understood the nature of their ocular problem (92% vs. 71%). History of utilizing medical services can be a useful measure of how likely a patient is to avail referred care, since those with more frequent visits tend to be the most proactive in seeking treatment.

Among subjects who followed through with their referral, a common suggestion was that LVPEI tertiary centers find a way to expedite the check-in process and see traveling patients earlier in the day to lessen the burden of travel on patients and their families.

In moving forward with this study, the revised questionnaire and database should be considered to improve the quality and utility of results. A more in depth comparison should be made between paying and non-paying patients within both the defaulting and non-defaulting groups once more responses have been collected, since understanding themes within both payment groups will help guide future counseling and decision making. Integrating the consultant's referral note into the NBEC online medical record system and introducing an easy way to document which patients have and have not accessed tertiary centers will allow for better continuity of care and will enhance LVPEI's understanding of how their patients respond to the thousands of referrals that are made from secondary centers each year.

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International Medicine Research

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Voices of the Voiceless: Battered and Homeless Women in South Korea

Introduction: The general characteristics of homeless men and women in Korea do not differ greatly from their counterparts in the U.S. The common reasons for being homeless for men include job loss, conflicts within family, lack of affordable housing, alcohol, and mental illness. These are the same reasons that caused increase in homelessness in Korea shortly after the Asian economic crisis in 1998. The gender difference phenomenon seen in Korea is also not unique. In Rochester, NY, the visible homeless, the ones who sleep outside, are predominantly male (1). Homeless women tend to sleep in shelters.

Williams's study in Phoenix states that domestic violence and low-cost housing shortages are the two main reasons for homeless women. She also concludes that the distinction between a "homeless woman" and "battered woman" is arbitrary, because many homeless women have a past history of abusive partners (2). Even though homeless shelter staff often argue that a homeless woman has different needs than a battered woman, the striking similarities in women's reasons for seeking emergency housing suggests that one cannot overlook at the underlying symptoms when providing services.

Objective: This study aims to understand the situations of women who are homeless in Seoul, Korea. Homeless women have invaluable insights to share with the government and non-governmental organizations regarding what they want and need to take care of themselves and their children. Constructing the women's stories and common themes across the sample population, this study hopes to provide crucial information and insight to inform how best to support these women.

Background: The limited literature on homeless women in Korea reveals the seriousness of their wellbeing and suggests services tailored specifically for the women. Some of the unique characteristics of homeless women include: sexual abuse, psychiatric problems, high stress level, and hopelessness. Many of the women have also been housewives, requiring job training in order to be independent. Shin's research found that homeless women are more likely to have received psychiatric treatment (3). Based on her findings on depression among homeless women, Shin suggests that homeless shelters create an environment and use a systematic approach to help the women manage stress. This study linked several factors such as "learned helplessness" to influence women's the successful job launching and resettling.

During and after a major economic crisis in 1998, 60-70% of the homeless were dependent on alcohol. About 70% of the homeless were in their 30s and 40s. 35.5% have been abused as a child or have parents who are alcoholic or have mental illness. The gender difference in the homeless population is seen internationally. Those who sleep in the streets are often men and dependent on alcohol. Women tend to be victims of domestic violence or have psychological problems in addition to financial instability. Most homeless women also sleep in shelters, not outside. Kim's study in 2001 reported that about 52% of homeless women have symptoms that require on-going psychiatric treatments. In addition to being homeless, these women probably have more stress possibly due to sexual abuse (4). This finding confirms Shin's conclusion that homeless women need services quite different from the pre-existing facilities, which target the needs of homeless men.

Methods: I interacted with a dozen homeless women and spent time with four of them on a daily basis. I collected information from participant observation and 5 interviews by volunteering in the homeless clinic, joining women's support group meetings, and going out at night with the street outreach team.

Results: In contrast to homeless men, homeless women tend to stay in shelters, receive assistance from organizations and form their own supportive community. Some general trends among the homeless women include family abandonment, domestic violence, and psychological or physical impairment. Of the dozen homeless women I encountered, groups of three and two women lived together. Some of these women shared their income and helped each other learn how to manage budget, raise children, cook and do other house chores. One person used to live with the others but could not stay with them due to some severe psychiatric issues. She still came frequently to see the group of women, getting food and assistance with housing situation.

On a given evening in the month of June, over 150 homeless men slept in the Seoul train station and nearby parks. One evening, we encountered three women. Two had some serious mental problems and were unresponsive to the outreach workers. One interacted with the outreach workers. She was quite angry with the police who asked her to move out of the park. She did not want any assistance because she did not wish to sleep in a shelter. In addition to these three encounters, I met five ladies who frequently came to the Homeless Outreach Center to hanging out. Each of these women had some noticeable mental and or physical disabilities. Two of the ladies lived together for several years and knew each other very well. They also called some others at the center using intimate terms like aunt, uncle, brother, and sister. They were very playful with each other, shared information on where they received decent free food, collectively assisted a fellow homeless woman figure out how to get a place, and shared snacks.

Conclusion: As some previous studies suggest, psychiatric and domestic problems are common in homeless women in Korea. This study shows that in efforts to re-create a home, some homeless women choose to live with others in a similar situation. By doing so, they gained a supportive network they had once lost when they left their families. Collectively, the women were financially more stable. They shared information on services and job opportunities. More importantly, they had each other to share their struggles as well as joys. The positive outcomes of communal living suggest that it can serve as a model for both homeless women and men who are seeking home. The current homeless shelters house 50 - 60 people in one giant room. Many prefer to sleep outside. Alternatively, the government has provided single rooms to some homeless people. Providing a shelter, however, does not necessarily solve the issue of homelessness. Often, people who have the government subsidized or free housing find their way back to the streets. A homeless person does not simply lack a place to stay. Rather, s/he lacks a home, a family, a community, which a physical place

cannot satisfy. Further studies on how homeless individuals re-create their support systems and re-integrate back to the society will provide invaluable insights on how best to assist others to bounce back.

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International Medicine Research

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An Assessment of the Availability and Utilization of Maternal Health Resources in Yantalo, Peru

Introduction: Maternal mortality is especially high in under-developed countries where women face significant challenges not present in more industrialized nations. These challenges are often a result of strong cultural beliefs and common societal practices, emphasizing the need to understand how a given population perceives and utilizes health care resources. When assessing healthcare access and utilization it is necessary to understand the cultural environment of the community involved in the study.

Objective: We aimed to quantitatively and qualitatively assess the availability and level of utilization of maternal health resources among women in Yantalo, Peru. Specifically, we hoped to answer three primary research questions: (1) What is the current level of information available to pregnant women in the community? (2) What is the current level of utilization of professional health care resources during pregnancy in the community? and (3) What are the motivations for the use/non-use of these resources from a cultural perspective?

Background: The average maternal mortality rate for the country of Peru is 98 per 100,000 live births, however, there are significant disparities in maternal mortality rate and births attended by a skilled professional between rich and poor populations within the country. An estimate of maternal mortality rate for the poorest groups is greater than 800 maternal mortalities per 100,000 live births. This is due, in part, to lack of access and under-utilization of health care facilities within poor, rural communities. Perhaps the most significant contribution to the underutilization of health care facilities in Peru is the reluctance of the population to use state-established facilities. This is largely a result of mistrust from the community because of an unwillingness of the state to understand and to respectfully accommodate the cultural traditions of the people. Through our research in Yantalo, Peru a poor, rural, jungle community of about 5,000 inhabitants located in the northern Peruvian Amazon in the Province of Moyobamba in the San Martin Region, we aimed to determine the current level of information available to pregnant women in the community and the utilization of professional health care resources during pregnancy in the community, as well as understand the motivations for the use/non-use of these resources from a cultural perspective.

Methods: From May 29th - July 5th we surveyed women 18 years of age and over who were currently pregnant or who already had at least one child. The surveys took place in the homes of women in the community and at the posta (clinic). Most of the surveys were done as a conversation because of the high illiteracy rates.

Results: 51 women between 18 and 80 (mean age of 36) were included in this study. 80% of these women were either married or living with the father of their child or children. Within the community, health care literacy and utilization of the local government-run health care center depended heavily on the age of the respondent, with a reference age of 40 providing the best distinction between groups. The younger generation of women were less likely to give birth either in their homes or on their farms (12% in women under 40; 65% in women over 40), more likely to go monthly to the health center during their pregnancies for scheduled check-ups (97% in women under 40; 36% in women over 40), and more likely to have used birth control at some point in their life (84% in women under 40; 29% in women over 40). To better accommodate the women of the community, the health center not only provides education (85% of women familiar with birth control learned about it through the health center), but also allows the father to be in the room for the birth and lets the mother choose her birthing position (30% prefer kneeling, 6% prefer sitting), neither of which are allowed at the nearby hospital.

Conclusion: Despite these efforts, resource limitations still acts as a barrier to health care. Lack of birth control alternatives means that 12% of women chose not to use birth control because of severe side effects to the available methods. Also, while condoms were in theory available from the health center, zero respondents mentioned using them (though no question specifically asked about condom use). There is much less resistance to using the current clinic in Yantalo from the younger generation. While we were not able to gather data on maternal mortality rates, this improvement is encouraging and shows promise for decreasing maternal mortality rates in this region and increasing maternal health. Currently, a new clinic is being built in Yantalo that will have access to more healthcare resources. With the shift in utilization we observed in the new generation we are hopeful that maternal health will continue to improve.

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International Medicine Research

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Netlife: Assessing Barriers to Mosquito Net Use in Senegal

Introduction: Netlife is a small non-governmental organization (NGO) dedicated to eliminating malaria in West Africa. The not-for-profit group's first and primary goal is to support sustained mosquito net coverage in Senegal. They have successfully collected and distributed 50,000 mosquito nets in rural southeast Senegal since 2008. In order to prepare for the next round of fundraising and distributions, it is necessary to measure the remaining demand for nets, the lifespan of the nets, and the success in reducing malaria. Additionally, it is important to assess the barriers to complete net usage to ensure maximum pay-off from these distributions.

Objective: Design and implement a culturally acceptable survey to accurately assess the barriers preventing the use of mosquito nets.

Background: In 2010 there were 174 million recorded cases of malaria in the world and 655,000 malaria deaths; 91% of these deaths were in Africa. In order to tackle this burden, distribution of insecticide treated nets (ITNs) has been a major focus across sub-Saharan Africa. ITNs have been demonstrated through numerous randomized clinical trials to significantly reduce morbidity and mortality from malaria by reducing human-mosquito contact. Senegal, one of the currently endemic countries, has had a national distribution of 2.2 million nets in 2009 as well as smaller-scale distributions such as those performed by the NGO Netlife. Six months following the nationwide mass distribution, it was found that about only 22% of the population owned at least one bed net per sleeping space. Therefore, despite these distribution campaigns, many Senegalese still do not have access to a net and thus further distribution efforts are critical.

Methods: Prior to arriving in Senegal, we designed a rough draft adaptation to the World Health Organization's Malaria Indicator Survey. Adaptations included the addition of several qualitative questions about why the nets are liked or disliked. Once in Kedougou, Senegal—the target region for our survey—we did a trial run of the survey with a local resident. We also hired several people to translate the survey into Pulaar, the local language as well as local project managers to oversee the administration of the surveys. We travelled to the villages that were randomized for the survey in order to gain permission and support from the village chiefs and collect population censuses. We travelled to the local nurse-run health posts for data on malaria incidences. We ran a full-day training session for our hired surveyors, stressing in particular how to properly conduct a largely qualitative survey and the importance of refraining from leading answers. The survey will be conducted during the month of September, toward the end of rainy season. Data will then be analyzed from the University of Rochester.

Results: After trialling the survey we discovered that some of the questions required culturally sensitive restructuring in order to elicit more forthcoming answers. For example, we hope that by asking about net coverage for sleeping spaces, rather than the standard questions about who slept where, we will obtain more straight-forward and accurate information on the extent of ITN coverage. Although data is still pending, based on our observations during our time in Senegal, we expect to find that the biggest barrier to mosquito net use is access. We also expect to find that while many people have complaints about nets, such as that they are hot, or the insecticide “makes them sick,” if people have nets, they use them.

Conclusion: Since 2003, Netlife has developed strong relationships and collaborations throughout the Kedougou region working to reduce malaria. We hope that the results of this survey will help us to continue that work by clarifying how many more nets are needed as well as barriers to full, proper use of available nets. Some of these barriers may be the target of future interventions. Additionally, while the results of this survey will certainly be directly useful for Netlife as an organization, the results from this survey are widely generalizable to rural areas in West Africa and beyond.

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International Medicine Research

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Online Mental Health Survey of MSM in Ho Chi Minh City, Vietnam

Introduction: In the current epidemic stage of HIV prevalence in Vietnam, the mode of HIV transmission has shifted from among injection drug users to other minority groups such as female sex workers and men who have sex with men (MSM). These groups are marginalized by society and receive little to no attention from public health services. Yet, they play an important role in determining the future state of the HIV/AIDS epidemic.

Objectives: This quantitative study aims to explore different aspects of mental health and risk behaviors among MSM in Ho Chi Minh City, Vietnam. Many psychological health concerns of this population often have been overlooked in the prevention, treatment and counseling of HIV/AIDS. Hence, the survey results will help to create safe, accessible, and affordable mental health services for MSM in the future.

Background: One of the biggest problems in fighting the HIV epidemic in Vietnam is the lack of education and counseling for at-risk populations. Individuals who identify as MSM have to deal with even greater social stigma for their sexual practice. For MSM who come from low socioeconomic backgrounds, they have very limited access to health care and receive almost no psychological services. In an effort to reduce HIV transmission and improve outcomes of HIV/AIDS care, more efforts should be directed toward understanding the needs of this population, especially focusing on mental health screening and counseling.

Methods: Potential subjects for the study were recruited through websites catered to the MSM community. They were asked to fill out an anonymous online survey, which consisted of five standardized mental health questionnaires translated into Vietnamese. The PHQ-9 and GAD-7 Scores were used to evaluate depression and anxiety symptoms, respectively. The Rosenberg Self-Esteem Scale was used to assess the level of self-esteem of participants. Alcohol consumption level was recorded using the AUDIT form. Post-traumatic stress was evaluated using the Primary Care PTSD Screen from the National Center for PTSD. Other basic demographics were also recorded to make regional and socioeconomic comparisons.

Results: The majority of more than three hundred MSM who completed the online survey self-identified as gay men. The preliminary results revealed that 44% of those subjects screened positive for post-traumatic stress (*Figure 1*). The GAD-7 scoring identified 175 men who screened positive

for anxiety, of which ~45% had moderate to severe anxiety (Figure 2). With the PHQ-9 scoring, 48 men screened positive for clinical depression, of which ~90% had moderately severe to severe major depression (Figure 3), and ~87% experienced post-traumatic stress and anxiety in addition to depression.

Conclusion: Vietnamese MSM have serious mental health concerns that mostly have been neglected due to social stigma and lack of access to health care. These factors negatively affect their quality of life and often result in risk behaviors that could potentially lead to HIV transmission and poor HIV treatment outcomes. Thus, psychological services should be included as part of standards of care for the MSM population.

Figure 1

Anxiety

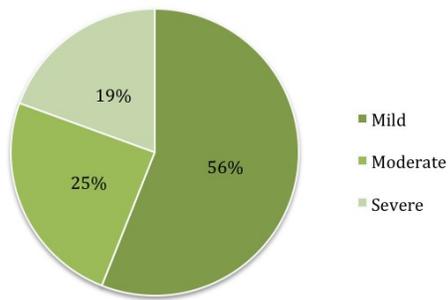


Figure 2

Post-Traumatic Stress

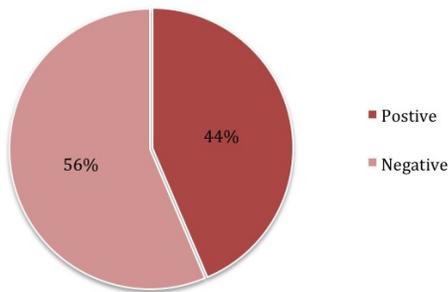
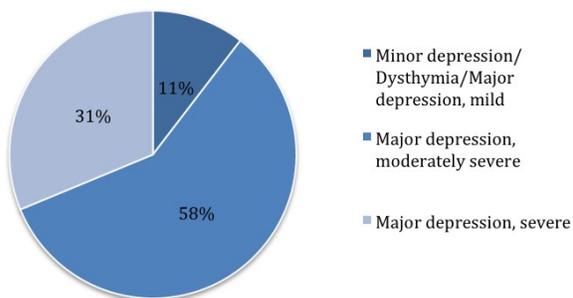


Figure 3

Depression



International Medicine Research

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The Savelugu School for the Deaf Northern Region, Ghana: A Retrospective Study of Postlingual and Prelingual Hearing Loss

Introduction: Disabling hearing loss in children, as estimated by the World Health Organization has more than doubled from 120 million in 1995 to 278 million in 2005, and two thirds of people with hearing impairment live in developing countries such as Ghana.¹³ If early hearing loss is left undetected, even mild or unilateral hearing loss can result in social, emotional, and behavioral problems, as well as lags in academic achievement and delayed speech and language acquisition.^{2,3,19} In Ghana, intervention includes sending children to schools for the deaf, which has its own limitations on educational success for the deaf. In the United States it has been reported that 95% of children educated in deaf schools only reach a reading age of 9 years.¹⁶ Due to poorer educational systems in Ghana, this figure is probably even less.

This is a retrospective study of 286 students at the Sevelugu School for the Deaf in the Northern Region of Ghana. In order to be admitted into the deaf school, students are referred from their families or the hospital and then hearing tests are performed. The cause of their deafness is generally unknown because their medical records are very poor. Also, because for most of the children their hearing loss took place at a young age, they cannot recall the exact age or circumstances of their deafness.

Doctors at the Tamale Teaching Hospital and throughout Ghana believe that malaria and meningitis are two major causes for the extremely high prevalence of deafness in Ghana, particularly in children. In order to determine the effect of malaria and meningitis on hearing loss in children, a prospective study must be done. This would require children who are infected with these diseases be followed for an extended period of time, with regular audiograms for surveillance of any resulting hearing loss. The circumstances surrounding the Sevelugu School for the Deaf does not allow for such a study at this time because these children already have profound hearing loss.

Still, the large population of deaf children at the school offers a subject group with possible interesting and helpful insight into the nature of hearing loss in the Northern Region of Ghana and Africa as a whole. Similar retrospective studies have been done. A Nigerian study proposed malaria as the cause for 0.4% of hearing loss cases.⁷ Another study in New Guinea found cerebral malaria

and meningitis combined to cause 11% of hearing loss.¹ Finally, many studies have demonstrated a proportion of hearing loss caused by non-specific ‘fever’ or ‘febrile-illness’: 5.8% in Nigeria⁷, 15.4% in Gambia¹¹, 19% in Ghana⁴, and 18.3% in Nigeria^{6,20}

The goal of this study is to determine the amount of children who are prelingual versus postlingual, which can be done objectively by determining if the children have speech. Because children begin to speak between 1.5 to 2 years of age, a deaf child with speech lost their hearing after this age.¹⁴ If a child cannot produce any speech, then the child suffered profound hearing loss before this age. By determining this statistic from the children at the deaf school, we can compare the result with that of other developed nations.

It is our hypothesis that there will be a significant percentage of postlingual hearing loss in children at Sevelugu School for the Deaf, as representative of hearing loss in Ghana as a whole. It is well established that the antimalarial drug quinine is ototoxic and this accounts for most of the hearing loss sequel, but reports suggesting that symptomatic hearing loss as a result of the malaria parasite itself has been lacking further investigation.²⁰

Although data is lacking on the prevalence of deafness due to such infectious diseases and malaria, malaria and meningitis have been reported as causes for hearing loss in African countries such as Uganda.⁸ Furthermore, recent research suggests that 50% of hearing loss in developing nations is preventable, suggesting the significance that the infectious pathogens of malaria and meningitis have on hearing loss.¹⁷ Contributing to the increased prevalence of these pathogens, the medical treatments and vaccinations for viruses, parasites, and other pathogens that may lead to hearing loss are more advanced in developed nations than in Ghana.

It should be noted that this work is a small element of a much bigger project. There are four schools for the deaf in Ghana: Sevelugu, Wa, Tongo, and St. John’s. The Starkey Foundation in Minnesota, United States is donating hearing aids to all of the children at these schools with profound hearing loss. In order to make this possible, Dr. Murphy and his team at the Tamale Teaching Hospital has been visiting the schools and taking ear mold impressions, which then get shipped to Starkey for making of the hearing aids. While at the schools to take the ear mold impressions, this research is being conducted in hopes of connecting the dots for childhood hearing loss and uncovering information that may help in the future for prevention.

Methods: We visited the Sevelugu School for the Deaf and collected a history of the children with hearing loss and hearing aid impressions. The same questions were asked during each session and interpreters used sign language to communicate with the deaf children. The interpreters were the teachers and Headmistress at the Sevelugu School for the Deaf.

The primary focus was the hearing loss age of onset. Although most did not remember an exact age because they were too young or have forgotten, some were able to recall a particular age or if they were born deaf. We determined if they were postlingual or prelingual by having them attempt to speak. Those that could not produce intelligent speech were recorded as prelingual, and those that could form “deaf speech” were recorded as postlingual. If the student and file confirmed they were born deaf, they were recorded as prelingual-born deaf. Some could recall a particular illness, such as malaria or cerebral spinal meningitis (CSM), which accompanied the hearing loss. Others could only recall general sickness, convulsions, fever, headache, or similar symptoms. Still others could not recall any sickness at the time of hearing loss. Observations of Waardenburg traits, which include

blue eye color, heterochromia, defect linea alba, white forelock, and positive family history, were also recorded.

The collected data was organized in an Excel spreadsheet. Analysis of data was performed by general observation of trends and simple statistics to determine percentages. These are compared to similar data and percentages for children with hearing loss in other parts of the world.

Results: Of the 287 children for which this information was gathered, 199 were prelingual and 88 were postlingual. Therefore, 69.3% lost their hearing before or around age two whereas 30.7% suffered hearing loss after this time, as determined by the presence of deaf speech.

From the children that were found to be prelingual, 50.3% (100) were reported as being born deaf, 30.7% (61) reported having either malaria (4), convulsions (21), CSM (5), or sickness (33) or a combination of these at the time of their hearing loss. There were many that did not know what caused their deafness.

From the children that were found to be postlingual, 78.4% (69) reported having either malaria (7), convulsions (16), CSM (8), headache (2), fever (1), otitis media (1), pain in ears (2), chicken pox (1), Mumps (1), sickness (38), or a combination of these at the time of their hearing loss.

A total of 45.2% (133) students of both the prelingual and postlingual group could recall some sickness at the time of hearing loss. 21.8% (64) recalled malaria (11), CSM (13), or convulsions (40) at the time of hearing loss.

Of the 287 children examined, 6 (2%) met at least one of the criteria for Waardenburg Syndrome. In order to take the ear impressions, 46 (15.6%) children needed to have wax or a stone removed, some of which came to the hospital for removal.

Discussion: This study of the Sevelugu School for the Deaf offers insight to the timetable for hearing loss in the Northern Region of Ghana, which is a microcosm of Sub-Saharan Africa. We have uncovered an estimate of the age of onset of hearing loss in the region, specifically 69.3% prelingual and 30.7% postlingual. This crude percentage suggests that about 2/3 of children with hearing loss became deaf before they learned how to speak, before 2 years of age, whereas about 1/3 of children with hearing loss became deaf after they learned how to speak, after 2 years of age.

Postlingual deafness can have many etiologies including genetic, infectious, autoimmune, anatomic, traumatic, ototoxic, and idiopathic factors. Due to the environment and prevalence of infectious diseases including malaria and cerebral meningitis, postlingual hearing loss is relatively common. *Plasmodium falciparum*, the causal parasite of malaria, is not endemic in first world countries as it is in Sub-Saharan Africa. Similarly, pathogenic causes of meningitis are not vaccinated in these third world countries as they are in the United States and well-developed nations.

Of the prelingual group, 30.7% attributed the hearing loss to a sickness, often a non-specific febrile illness. Due to the common symptoms of headache, fever, and convulsions, we hypothesize the common illness to be a mix of malaria and meningitis due to their prevalence in the region, especially affecting young children. Likewise, 78.4% of the postlingual group recalled some illness at the time of their hearing loss. Many could specifically recall specific illnesses including malaria, CSM, and mumps, while the majority could only recall a non-specific febrile sickness. This

staggering percentage is a testament to the environmental infectious endemic in Africa, a contributing factor to increased incidence of deafness in developing countries as a whole.

A total of 133 students (45%) at the Sevelugu School for the Deaf reported some form of illness at the time of hearing loss, and 21% could more specifically recall malaria, CSM, and/or convulsions. Sudden SNHL at a young age is most often pathological in origin, and the history of symptoms is most important for the diagnosis. Malaria and meningitis are rampant in Ghana and Africa, and the histories from the deaf children at Sevelugu School for the Deaf reporting sickness with symptoms of malaria and meningitis at the time of hearing loss is more than just coincidence. We believe this research warrants additional studies on the effects of malaria and meningitis on hearing loss. A prospective study with children infected with malaria or meningitis at a young age would be more specific than our retrospective studies of the deaf schools.

With this information, we hope for heightened awareness of the detrimental effects of malaria and meningitis. Hearing loss in children leads to lower educational levels and social normalcy. Although many cases are congenital and genetic in origin without any means of prevention, infectious agents pose as a preventable source. The technology and medicine have been developed but is not readily accessible in areas of most need. Medication and vaccination distribution should be a goal for the future as well as education of germ theory and mosquitoes as a vector for malaria. Simple measures taken such as the use of mosquito nets and insect repellent can go a long way in malaria prevention and possibly hearing loss.

The six children with traits consistent with Waardenburg Syndrome offer an additional piece of information that may offer interesting follow-up work. Because this has an autosomal dominant inheritance, there may be areas within the northern region of Ghana that have an increased incidence of Waardenburg Syndrome. More specific research into the specific villages that these children are from and possibly even the tribe they belong may lead to common ancestral lines of the syndrome.

In order to better understand the significance of this data, further research must be done not only in Africa but also around the world. There is not sufficient data about the statistics of prelingual versus postlingual deafness in children in both Africa and the world. This information is required to properly understand our findings. Still, we speculate that the great number of postlingual deafness found in the children at the Sevelugu School for the Deaf in the Northern Region of Ghana is representative of the prevalence of infectious agents, most likely malaria and meningitis, which have the potential to cause hearing loss throughout Africa.

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International Medicine Research

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Coronary Interventions Performed in an Indian Community Hospital
*(Previously entitled: "30-day Outcomes in Percutaneous
Coronary Interventions in an Indian Community Hospital")*

Introduction: This study aimed to analyze the procedural success rate of percutaneous coronary interventions (PCIs) completed at the Care Institute of Medical Sciences (CIMS) Hospital in Ahmedabad, India. It also sought further understanding as to why coronary heart disease (CHD) is so prevalent in India.

Objective: Initially, this study sought to determine 30-day outcomes of patients who received a PCI. In particular, it intended to compare success rates between CIMS and the Cleveland Clinic as well as contrast outcomes between men and women. Finally, the study hoped to assess which lifestyle risk factors were most contributory to the high rate of CHD in north Indian urban centers.

Unfortunately, this project was not completed to entirety due to unforeseen circumstances. Consequently, this abstract reflects aspects of both the intended procedure, as well as the actual tasks performed.

Background: Heart disease is the number one killer for men and women in India; studies have indicated that India's population will account for 60% of the world's cases of heart disease. Such ailments have promoted the use of PCI. Therefore, understanding the efficacy of this treatment specifically in an Indian population is necessary. This is particularly true in light of the high levels of numerous risk factors that already exist in India, such as diabetes. In fact, a recent study suggested Indians have higher rates of adverse events following a PCI when compared to other Asians.

Research was performed at the Care Institute of Medical Sciences. This hospital administers over 7000 angiograms every year as well as over 1500 cardiac interventions. It is located in Ahmedabad, India's seventh largest city and home to over six million residents.

Methods: Ultimately, this project revolved around the use of the hospital's electronic records program, *Victory*. Individual datasheets were created to assess various aspects of the hospital's care and to study the demographics of patients receiving PCIs. *Victory* was also used to create datasheets on the medications relevant patients were prescribed during their care and over follow-up. Microsoft Excel was used for further analysis.

Results: Of note, this study found that men who underwent a PCI procedure outnumbered women by a ratio of over 5:1. This figure was similar in terms of hospital admittance in the occurrence of an acute myocardial infarction. In terms of medication, this study found that nearly all patients who received a PCI at CIMS between August 2010 and July 2011 were prescribed a statin (97.8%) and dual anti-platelet therapy (98.7%).

Conclusion: Evidence suggests that while heart disease ails both men and women, men are more likely to report to a hospital and receive treatment. Ultimately, this translates to a worrisome disparity in terms of treating heart disease between men and women. This project also suggests that cardiologists at CIMS are prescribing appropriate post-procedural medication to patients who undergo PCI.

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International Medicine Research

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Perceptions of a Healthcare Facility and Barriers-to-Care in Rural Dominican Republic

Introduction: According to the World Bank, low-and-middle income countries account for about 90% of the global burden of disease, but only 12% of global health spending. This inequity is not accounted for by the simplest explanations involving the lack of resources and knowledge.

In order to address global health disparities at a grassroots, community level, interventions, Peters et al. provides a framework for access-to-care as four dimensions:

1. Geographic accessibility
2. Availability of provision of care
3. Financial Accessibility
4. Acceptability in Cultural Context

This project seeks to apply this framework in a specific setting.

Background: The Dominican Republic has basic health indicators that lag far behind those of industrialized countries, with the poorest quintile of the population alluding to several of Peters' access-to-care barriers in WHO's 2003 World Health Survey. Peace Corps Volunteers posted to rural areas of the country noted that rural hospitals often appeared empty and unused. Los Claveles is one such rural community, located in close proximity to a major health resource called the Alta Mira Hospital.

Objective: The objective is to explore how community members of a rural community in the Dominican Republic use a major healthcare resource as affected by barriers to care.

Methods: Investigators were first introduced to the Los Claveles community while creating a community map, after which household interviews were conducted with each available household of the estimated 35 community households. Informal-style interviews were used to encourage subject guidance and discourage interviewer bias. For recording, the interviewer used minimal note-taking to decrease suspicion in a population that has never been studied before.

Interview responses were transcribed for coding and sub-coding, which were finally categorized into the four components of Peter's framework for analysis.

Results: Out of the estimated 35 households of Los Claveles, 29 households were interviewed, and 27 interviews were completed. Eighteen of these households (67%) reported a lack of use of the Alta

Mira hospital by one or more household member. The barriers cited for this lack of use represent Peter's four dimensions in the following manner:

Barrier-to-Care	Number of Responses	Percentage of Responses Given
Geographic Unavailability	1	3.0%
Unavailability of Care	13	38.2%
Financial Inaccessibility	5	14.7%
Unacceptability	15	44.1%

Of note, unique barriers were cited for each category. Common forms of unacceptability (44.1% of responses) included report of negative past events, community perception of the facility's doctors as inattentive or lacking expertise, and the idea that hospital healthcare was unneeded. Unavailability of care (38.2%) included a lack of medical specialty to address unique problems, lack of equipment, unavailability of appointments with recommended doctors, and better availability of alternate health resources ranging from home remedies and pharmacies, to other healthcare facilities in larger in-country cities and abroad. Financial reasons (14.7%) most commonly cited a lack of insurance coverage, and the sole geographic barrier cited (3%) was a lack of an ambulance vehicle. Further analysis is pending.

Conclusion: This study provided insight on barriers faced by members of a rural community in accessing the geographically nearest hospital available. According to the results, the largest barriers reported were cultural unacceptability (44.1% of responses) and unavailability of care (38.2%). Unavailability of care can be interpreted as a form of lack of resource, which is a major known contributor to global health disparities. Notably however, unacceptability represents an even larger portion of barriers listed, and may allude to the complex relationship between care-delivery and care-reception.

It should also be noted that the flexibility of informal-style interview method allowed for considerable variance in the way subject responses were presented, and therefore may result in analysis discrepancies and inaccuracies.

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Medical Humanities Research

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The Art of the Physical Exam: Building Trust and a Diagnosis Through Hands-on Medicine

Introduction: The art of the physical exam is a combination of performing maneuvers using proper technique to elicit information about a patient's health status and the ritualistic connection created with a patient through touch. Using the skills of observation, auscultation, percussion, and palpation, physicians can gather a great deal of data about a patient's illness, all while developing a relationship of trust and confidence between a doctor and their patient through this ritual. Currently there is a great debate concerning the value of the physical exam in the setting of modern medicine. Newer generations of doctors believe these untested, classic techniques are not useful and are becoming obsolete. On the other side, older generations of physicians who have "grown up" using the physical exam as their major diagnostic tool attest to the value of these maneuvers. As this debate ensues, the art of the physical exam is beginning to disappear from everyday practice as the number of "believers" and willing teachers continues to shrink.

Objectives: In order to increase my personal knowledge of the art of the physical exam, I worked with Dr. Bilal Ahmed and Internal Medicine residents at Highland Hospital. Shadowing these knowledgeable physicians gave me ample opportunity to learn more about the proper execution of exam techniques and to witness the power of the physical exam in developing the doctor-patient relationship. Furthermore, I worked to gain more insight into the pros and cons of using the physical exam versus medical technology in the assessment and treatment of a patient.

Methods: The majority of my learning occurred through one-on-one bedside teaching and attending "Sherlock Holmes Rounds" with residents. Using an organ systems-based approach, I was able to examine a wide variety of patients and improve my skills for examining a patient regionally and as a whole. I was also able to observe Dr. Ahmed's bedside manner directly and witness how it impacted the relationship between him and his patients.

Results: Through my work with Dr. Ahmed I truly learned the value of taking time to directly examine a patient, versus initial review of the "iPatient" via their electronic records, and how this can greatly impact the way in which symptoms are investigated and what diagnoses are added to the differential. Furthermore, performing the exam helps to provide completeness to the visit and can start to build trust between a doctor and their patient.

Conclusions: This summer project helped me achieve my goals of learning more about the art and value of the physical exam in modern medicine. It also raised a number of questions in my mind that

I think we, as a medical community, need to consider carefully, especially as we continue to increase our use of medical technology in the diagnosis and treatment of patients.

Should work be done to fully assess the usefulness of the physical exam? Would building trust in these techniques rebuild our confidence in the physical exam and ourselves as physicians? In the era of modern medicine, do patients truly value the use of touch over technology in their treatment? How will we find a balance between using technology in medicine and maintaining an intimate, trusting relationship with our patients?

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Medical Humanities Research

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Medical Humanities

From Rochester to Iowa: Perspectives

Introduction: The narrator explores the events leading up to and including an extended shadow of a rural family practice doctor in small-town Iowa. Throughout the story the narrator struggles with his own transition during the 2011-12 school year of moving from a rural area to Rochester. By returning to Iowa he not only gains perspective on his own life but also on the role of the health care provider.

Objective: The project aimed to compare and contrast the rural and urban doctor. The comparison was intended to take the format of a creative non-fiction narrative that uses introspection as well as direct observation to develop an assessment of differences in regional healthcare. As a final project, a series of self-contained short stories cataloguing each shadow was originally expected. Together these stories could offer a broader view of similarities and differences between rural and urban medicine. As secondary goals, the shadows could provide the author some guidance in deciding what type of medicine to ultimately practice. Finally, by chronicling the experiences in written narratives, the author's writing skills and ability to communicate medical concepts would be developed.

Methods: Prior to departing for Iowa, several doctors were contacted to determine their willingness to be involved in the project. Of those contacted, three expressed interest: two family practice doctors practicing in small towns ranging from 1,600 to 8,000 people and an ER doctor in a town of 60,000. I shadowed each doctor for three days. Each was asked a series of questions concerning their work and personal lives. Extensive notes were taken. After gathering enough information, I synthesized the notes into a written narrative that catalogued my experiences. I was able to merge the observations with my own personal reflections on rural vs. urban life and healthcare. Email contact with Dr. Brown Clark was maintained such that she could guide my project as needed over the summer.

Results: The finished product focuses on the first shadow of the summer. The additional shadows are used only to support observations made during the initial experience. It was found during all the shadows that the actual practice of medicine does not differ significantly in the limited scope that was observed. Instead, it is the role the physician plays in their community that differs. Small town doctors serve enormous fractions of their community and can be extremely versatile. Comparatively, doctors in Rochester often serve miniscule fractions of the community and tend more towards specialization. Secondary goals of determining which field of medicine to practice in, developing writing skills, and integration of writing into the author's career were also achieved. Finally, significant personal growth resulted from introspection leading up to and following the shadow.

Conclusion: The actual practice of medicine in rural Iowa and Minnesota differed very little from what I have learned in Rochester. Instead, I found the role the rural doctor takes in their community is what distinguishes the healthcare in the two regions. Rural doctors serve as pillars of health care that accept enormous fractions of their communities as their patient load. This is a phenomenon that I have not yet observed in Rochester.

Medical Humanities Research

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Blood Under the Microscope: The Life and Works of William Hewson

Objective: The aim of this paper is to provide a comprehensive narrative of the life and works of William Hewson from both a historical and medical vantage point. It is the hope that readers discover an appreciation and even awe for the historical research of individuals such as Hewson, which have made modern medical standards and practices possible.

Background: William Hewson (1739-1774) was a British surgeon, anatomist and physiologist. His talent in anatomy was initially recognized during his early work under John and William Hunter, brothers and leading anatomy professors of the time. Hewson entered into a teaching partnership with William Hunter but following a conflict between them in 1772, Hewson decided to open an independent school of anatomy. In addition to his role as a lecturer, Hewson is best known for his scientific research on the properties of blood and the lymphatic system. He defined several properties of the erythrocyte with the use of a microscope and was the first to isolate fibrinogen, which he described as 'coagulable lymph', from the blood. Additionally, he recommended paracentesis of air for the correction of pneumothorax and proved the existence of lymphatics in birds, fishes and amphibians. For these latter achievements, Hewson was elected to the Royal Society and awarded the Copley Medal. Though Hewson died at the young age of 35 from sepsis acquired following a dissecting wound, his legacy has continued. To this day, many credit his early discoveries of blood clotting to have significantly advanced the field of hematology and Hewson is regarded as the 'father of hematology'.

Methods: The majority of research took place in London, England during the summer of 2012. Primary sources were made available through members of the Hewson family, the Royal College of Surgeons Library, the Wellcome Trust Library and the American Philosophical Society. Secondary sources were consulted through Edward Miner Library and online catalogs. Places of note as related to Hewson's works were visited.

Conclusions: In the space of only five years, Hewson was said to have created "an entire new history of blood and its phenomenon in the living body" (1). These accomplishments are situated among a notable history of eighteenth century medicine and certainly deserve continued recognition.

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Medical Humanities Research

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Barriers to Recruiting the Chinese Immigrant Population for a Qualitative Study

Introduction: The body of literature focusing on the recruitment and participation of ethnic minorities in research studies has grown. This is primarily since the recognition that low participation numbers in health-related studies yield data that may be unreliable in affecting change in these communities. Despite this impetus, commentary on both the difficulties of recruiting specifically Chinese-American immigrants and effective strategies to recruit this ethnic minority still lack. This paper seeks to add to the nascent literary body regarding challenges recruiting immigrant Chinese-Americans in qualitative research.

Objective: To describe methods used in and barriers to recruiting a population of Chinese-American immigrant parents, based in the Rochester, NY area for a study involving one-on-one interviews.

Background: Though there is a growing body of literature on recruitment of ethnic minorities in research studies, fewer resources on the specific participation of Asian-Americans in research studies exist. Significant barriers to recruitment include language and cultural barriers as well as lack of understanding about what the research study entails^{3,4}. There is an even smaller library of literature on the barriers to participation of Chinese-Americans in studies. Cited substantial roadblocks to participation of this demographic include misunderstanding of research goals and purposes, language and cultural barriers, and mistrust of western physicians. Most of the reported recruitment challenges center on clinical trials, however. Only a handful of papers exist that consider recruitment struggles of immigrant Chinese-Americans into qualitative studies.

Methods: The goal of this qualitative study included 15-20 one-hour in person interviews, June – July 2012, of Chinese-American immigrant parents from mainland China who speak Mandarin and have lived in the United States for at least three years. This population was recruited in order to gain perspective on their understanding of what constitutes a healthy baby. The primary recruitment strategy relied on Mandarin-based print contact, such as flyers and emails, as the main form of outreach to the desired study group, though multimedia approaches were incorporated into recruitment efforts. Additionally, community organizations were approached both in person and via phone or email for assistance in dissemination. In addition a local Mandarin medical translator identified potential candidates among patients for whom she provided service and provided them with study flyers. The study investigator, as the main point of contact for individuals interested in participating, was bilingual and well-versed in the cultural nuances and mores of this ethnic group. Those who screened as eligible as determined by a screener and provided informed consent were enrolled in the study and participated in a one-hour interview conducted in Mandarin and audio-taped for more in-depth analysis.

Results: Of the desired 15-20 interviews (with 10 interviews considered the minimum required for feasible preliminary analysis), only 2 were completed within the 8 week research period. Six individuals contacted the research team regarding the study. The distribution of these 6 are as follows: 1 refused to participate (and whose eligibility status is unknown due to early withdrawal), 1 requested to help with the study instead of participating, 2 did not fulfill subject criteria as conveyed by the research flyer, and 2 qualified and completed interviews. It was determined that most, if not all, of these communications with the research team were prompted by research flyers in either residential communities or educational institutions. Four individuals, who were identified and whose contact information were collected by the medical translator (constituting a deviation from protocol and not an intended recruitment strategy), were contacted by the research team in the form of phone calls, email, and mail service. One refused to participate and 3 did not respond to communication efforts made by the research team. Of the 3 local ethnic organizations identified as key channels to the targeted study population, 2 failed to respond to requests made by the research team for assistance advertising the research study. 2 of the 4 organizations contacted electronically failed to respond to requests to advertise the research study. The other 2 pledged to advertise but electronic posting of the ad could not be verified.

Conclusion: Several roadblocks to successful recruitment and completion of the study were identified throughout the study's 8 week course. The following are highlighted as the most challenging by the research team and may potentially require the most focus to maximize recruitment in future studies within this locale: 1) 2 months time allotted for recruitment and research was insufficient to yield suitable research data. Generous increases in both front-end and back-end timelines for the study are essential to successful identification of potential participants given challenges in recruitment faced by the research team. 2) There are only 1,300 local Chinese-Americans, with fewer eligible for the study. The small number of local culturally-centered organizations limited access to the targeted community. Establishing connections with local community leaders prior to study initiation may help bolster support and interest from the targeted community. 3) Outreach to individuals identified by the medical translator went unreturned. Two of 3 local Chinese organizations failed to respond to requests for help. Involving and liaising with key community leaders may help increase response rates. 4) Passive recruitment alone is not enough to meet recruitment needs for this demographic as few individuals responded. Active recruitment, possibly based at a highly trafficked community fixture, may yield more promising recruitment numbers. 5) The sensitive nature of the research topic may have discouraged participation.

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Medical Humanities Research

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Social and Psychological Isolation in URSMD Medical Students

Introduction: I believe that many students experience feelings of isolation as they transition from pre-medical school roles to their new place within the medical profession. As first year students, we are caught at a pivotal point between our “before” and “after” lives- no longer a part of the non-medical sphere that many of our friends and family come from, but also not yet ready to fully participate or understand the intricacies of medical culture. The summer between first and second year of medical school represents one of the few moments of possible peace in a decade-long process of professional development; a moment to step back and reflect on the experiences and pitfalls of learning how to practice medicine. In this project, I addressed one of the more surprising and emotionally important issues that I experienced during my first year of medical school- a feeling of isolation derived from transitioning from a familiar role in society to a new one that changed how I relate to friends, family, and patients.

Objective: The primary goal of this project was to address the cognitive dissonance I experienced during my first year of medical school surrounding the theme of isolation. Ultimately, I hoped my reflections on this topic would help me form a coherent and mature concept of how I will respond to the elements of isolation I expect to encounter in my career as a physician. In addition, I conducted an anonymous survey of URSMD students at the beginning of the summer. I hope that the anonymity of the survey allowed students to share personal feelings that they may not admit to in other situations, enabling me to present an honest and unbiased representation of our class's thoughts on their experiences with social and psychological isolation during medical school.

Background: Despite the importance of emotion in medicine, many articles have documented the increasing detachment of physicians over the past few decades. A primary stumbling block in medical school for many students is cognitive dissonance, which occurs when new ideas, values, or experiences challenge an individual's previously held beliefs. Resolving the cognitive dissonance, which is essential for developing healthy emotional and cognitive responses, requires self-reflection to evaluate the conflicting beliefs and either accept or reject one belief or synthesize the two in a way that allows for cognitive equilibrium. The use of reflective writing stimulates this introspection and gives individuals the opportunity to assimilate unfamiliar emotions, concepts, and experiences that they encounter.

Numerous scientific articles catalog the dangers of physician “burnout,” depression, and emotional detachment on patient outcomes and physician quality of life measures. However, few

articles seem to address the idea of isolation in medicine. Physicians have reported feeling isolated in many ways- socially, cognitively, and physically. Aspects of medicine that contribute to these feelings include the division between medical culture and “lay” people, the pressure of solitary decision-making, and a lack of collaboration or interaction with other physicians and healthcare workers. Based on my personal experience and anecdotal reports, this idea of isolation is rarely discussed in medical circles. I think this idea warrants further research to understand better the prevalence of feelings of isolation, particularly among first year medical students who may be more at risk for these feelings due to their new experiences and attempts to transition into medical culture.

Methods: I created an online survey and disseminated it by email to all medical students at the University Rochester School of Medicine & Dentistry. Student surveys were anonymously collected and analyzed. I also spent 4 weeks during the summer solo hiking part of the Long Trail and Appalachian Trail in Vermont. During this time, I reflected on the isolation I experienced on the trail and compared it to my first year of medical school. Both before and after the hike, I used creative writing as a media to compose my thoughts on these experiences. I drew on the writings of environmentalists, physicians, scientists, and authors to enrich my perspective on this topic of isolation and incorporated many of their thoughts into my own writing.

Results: Surveys were completed by 125 students from all 4 classes and year-out/graduate students. All of the respondents reported feeling some type of isolation, whether it was social, psychological, or physical. In general, students from the 5 different class years reported a similar distribution of responses to most questions.

Conclusion: Based on the collected data and anecdotal evidence from student free responses in the survey, I conclude that most medical students experience many different forms of isolation throughout their 4 or more years of medical school. Isolation covers a wide range of experiences from ending romantic relationships to spending more time alone. Most students expressed the view that they expected some isolation during medical school. Across the 4 or more years of schooling, students reported similar levels of isolation and related experiences, suggesting that this is not a phenomenon limited to the first year of medical school.

Drawing upon the survey results and my experience solo hiking over the summer, I emerged from this project with a clearer understanding of isolation in medicine and the role that it is likely to play in my future career. I believe that a deeper appreciation for this aspect of the medical profession will allow me to recognize both the benefits and dangers of isolation. Finding time alone to reflect on experiences can be essential in resolving cognitive dissonance and progressing in life, while becoming preoccupied with one's social, psychological, or physical isolation can directly interfere with this ability to grow. Ultimately, my experiences this summer will help me use isolation more effectively as another tool to keep myself balanced and healthy as I continue in this career.

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Year-Out Research

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Infectious Disease

Perceptions of MSM of Color on HIV Vaccine Clinical Trial Participation

HIV/AIDS remains a worldwide pandemic with no known cure. Of the over one million people in the USA living with HIV, roughly 75% are men and the main route of infection remains men who have sex with men, or MSM (48%), (CDC 2008). Although Whites make up the majority of the US population, their rate of HIV infection is 225/100,000 versus 1,715/100,000 in African Americans (46% of those living with HIV) and 585/100,000 in Latin Americans (18% of those living with HIV), despite the fact that African Americans and Latinos make up only 12% and 15% of the US population respectively (CDC 2008). Though people of color are over represented in HIV acquisition, they are historically underrepresented in HIV vaccine clinical trials. This includes the House Ball community, a marginalized sub-population composed of MSM of color with high HIV and STD prevalence who traditionally do not access HIV and medical services due to institutional mistrust. A detailed, semi-qualitative survey assessing barriers and facilitators that arise when recruiting MSM of color for HIV vaccine clinical trial (VCT) research initiatives was administered with the purpose of gaining a full understanding of the environmental and social factors that influence this demographic so that an effective module for HIV education and prevention strategies, including increased participation in HIV HVTN clinical trials, can be implemented in the community. The survey was designed such that comparisons between MSM of color involved in the house ball, or “ball” community and those who are not can be ascertained.

Surveys were administered orally to qualified men (those indicating sexual activity with men, who personally identify as being of either African American or Latino descent, from age 18 to 50) at locations in Buffalo and Rochester, New York (AIDS Community Services {ACS}, AIDS Care (AC) & Men of Color Health Awareness {MOCHA}). Recruiting was done at weekly and monthly events held at ACS, AIDS Care, and GAGV (Gay Alliance of Genesee Valley). Flyers, hand bills, and other marketing materials were also posted and distributed at locations with high visibility for the MSM population in both Rochester and Buffalo. Survey sessions lasted approximately 45 minutes each and were conducted in a private, designated room at each location.

100% of individuals surveyed stated clinical research was both important and benefited their health and lifestyle, and most (86.5%) stated they would participate in an HIV VCT. Approximately 90% of individuals heard of VCTs, but only 10.8% of individuals ever attempted to participate in clinical research. Lack of participation and negative perceptions among MSM of color may be addressed by modifying current outreach practices for the demographic and increasing educational initiatives. For example, flyers were the primary way participants heard of HIV VCTs (78.3%), but no participants indicated flyers as an effective form of communication. Safety, information, side effects, and fear of contracting HIV were the primary factors determining HIV VCT participation, all of which can be addressed with increased educational outreach. It is important to note that though there were

significant differences for level of HIV risk between Ball community members and non-Ball members, there were not significant differences between their perceptions about VCTs and VCT participation. Investigation of additional perimeters must be conducted to determine any differences between the populations.

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Year-Out Research

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Pediatrics

Background: Children in out-of-home care have exponentially high rates of socio-emotional problems and long term health morbidity due to exposure to multiple childhood adversities. Youth in the general population who are engaged in structured activities have better academic and social outcomes and decreased rates of health compromising behaviors, such as drug use. Little is known about the opportunities for involvement in normalizing structured activities for youth in foster care and the possible positive impact these may have on peer and social relationships and health status.

Objective: To examine the impact of engagement in structured youth activities in a nationally representative sample of youth in the child welfare system.

Design/Methods: We performed a cross-sectional study of youth in foster care, aged 11-17.5 years, using the National Survey of Child and Adolescent Well-Being II, a nationally representative sample of children in the child welfare system. We examined a cohort of youth in out-of-home care for 18 months. We used multivariate regression analyses to examine the relationship between involvement in structured activities, as reported on the Youth Self Report, and youth's peer relationships (Loneliness and Social Dissatisfaction Questionnaire), drug abuse (CRAFFT screening test), depression (Children's Depression Inventory) social skills (Social Skills Rating System), and academic achievement (Woodcock-Johnson Test of Achievement **Results:** Among 134 youth in out-of-home care, 27% reported involvement in structured youth activities. Using multivariate regression analyses, adjusting for demographic factors and baseline performance for each outcome measure, engagement in structured activities was predictive of better peer relationships, lower risks of drug abuse, and lower rates of depression.

Conclusions: Youth in foster care have suboptimal rates of involvement in youth activities, and likely could benefit from structured activities that may have a positive impact on peer relationships and a reduced risk of drug abuse and depression. Pediatric providers can offer anticipatory guidance encouraging caregivers to recognize youth strengths and to seek opportunities for youth development.

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Year-Out Research

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Knowledge, attitudes, and behaviors surrounding HIV/AIDS among university student and detailed analysis of HIV/AIDS cases in Cusco, Peru

Background: There is no need to describe the massive global public health impact HIV/AIDS has had over the past 30 years. In many countries, including Peru, the incidence of HIV/AIDS is still increasing despite numerous public health initiatives. In Peru, about 70% of the population is under the age of 25. [1] Despite many education initiatives, data suggests that young people are not modifying high-risk behavior. For example, while *knowledge of appropriate condom use* has increased from 33% to 74% in the general population from 2000 to 2009, *actual condom use* among young women with a high-risk (non-marital, non-cohabitating partner) partner is still only 34% [2]. Efforts to educate and dispel myths about HIV/AIDS are imperative for prevention efforts among the younger, at risk population. Currently, the vast majority of data regarding HIV/AIDS in Peru comes from its capital, Lima, and more region-specific information would greatly aid local public health projects.

The city of Cusco is located in the Andes Mountains and is an extremely popular tourist destination. The young adult population of Cusco is largely students from both the city and surrounding areas. In addition to typical high risk behaviors that put them at risk for HIV/AIDS, they encounter a large population of ever-changing tourist, many of them young and looking for sex and drugs. The flux of tourists poses a unique route for transmission of STIs including HIV. In order to guide education and intervention efforts, we believe that the first step is a comprehensive survey assessing risk factors and knowledge of HIV/AIDS.

Objective: The first part investigation was to analyze case reports of HIV/AIDS in the past five years from Cusco, Peru to provide the most accurate and current community statistics possible. The second part was to use surveys to assess demographical information, risk factors, and HIV/AIDS knowledge among university students to better understand the target population for prevention efforts. The third part was to conduct focus groups with university students to assess what they identify as strengths and weakness of the sexual health education system to identify potential targets for improvement projects.

Methods: Part 1: Case data was provided by the Department of Public Health from their records archive. Data was gathered from case reports of HIV or AIDS at both of the public hospitals in Cusco

over the past 11 years. Data was collected, tabulated, and then analyzed. No identifying factors were collected.

Part 2: The HIV-KQ-18 survey was used to assess HIV/AIDS knowledge. It is a validated survey consisting of 18 true or false questions [3]. One question pertaining to natural skin condoms was omitted as that type of condom is not available in Peru. Surveys were administered to the three largest universities and three largest institutes in Cusco after having received approval from the schools' directors. Survey participants were randomly recruited and no compensation was provided. All participants gave oral consent and participation was voluntary. Participants were excluded if they had never been a university or institute student at a participating school, were under the age of 18, or over the age of 30. Completed surveys were excluded if the applicant did not respond to the age or gender questions or if they did not complete the true/false section for assessing HIV/AIDS knowledge. Statistical analysis was done using Excel and MiniTab. All statistical tests utilized 2-tailed analysis with an alpha level of 0.05.

Part 3: Focus groups were held at the University of Andina with approval from the school director. Participants were randomly recruited and no compensation was provided. All focus groups were anonymous and voluntary and participants gave oral consent. Participants were excluded by the same criteria as above.

Results: Part 1: We were able to gather case data of HIV/AIDS cases reported in Cusco between the years 1998-2010. The data only encompasses those who presented to one of the two public hospitals in the city of Cusco. Originally we obtained cases from 2011, but we were unable to ascertain if these were all the case reports from the entire year, and so we excluded this data from the final analysis. The overall reported incidence in 2010 was 80 in a population of about 300,000. There were 50 reported cases in 1998 in a population that has remained relatively constant. The incidence decreased from 1998 to 2002 and again from 2005 to 2007. In other years, it has been increasing, including from 2007 to 2010. Under-reporting has historically been a major obstacle to getting accurate data [4], and the case data likely represent a sub-set of actual cases in the region. The presumed method of transmission was consistently most often heterosexual intercourse, followed by homosexual intercourse. Cases were consistently more often in males than females, usually as a ratio of about 2:1. The most common presenting symptoms were tuberculosis, general wasting, diarrhea, or candidiasis.

Part 2: A total of 514 surveys were administered to students of 6 different schools. We hypothesized that the student population encompassed youths from all different backgrounds. The number of surveys done at each school was based on the relative number of enrolled students. After exclusion criteria were applied, 504 surveys were analyzed. Most respondents were from the two predominant universities in Cusco: Universidad Nacional de San Antonio Abad del Cusco, a public school (UNSAAC – 230 respondents) and Universidad Andina, a private school (187 respondents). In Peru, there is significant difference between the student population of public and private schools. Public schools are more affordable, require higher entrance exam scores, and have a higher proportion of students come from rural/marginal areas. UNSAAC had a higher percentage of students from rural/marginal when compared to Andina ($p < 0.01$). One other private school and three technical schools were also included. The relative student enrollment in the technical schools was low and thus the results were pooled. There is a discrepancy the number of respondents for certain questions, as there were omissions. There were also three questions added during the course, which were analyzed as a subset.

There were similar numbers of respondents of each gender (253 Females, 251 Males). The median age of students surveyed was 21. 146 responded being in a relationship, 346 were single. 350 (70%) were sexually active, 149 were not. 6 out of 350 sexually active respondents reported having same sex partners (1.7%). Overall, 112 respondents have had an HIV test (26.8%). Of those, 91 returned to get the result (81.3%). In terms of high risk groups, 31 out of 497 respondents (6.2%) admitted to having been forced into sex. Out of these 31, 10 have had HIV tests. 21 out of 498 respondents (4.2%) admitted to having sex in exchange for money, all males. Out of these 21, only 5 have had HIV tests. 95 out of 348 sexually active respondents (27.3%) admitted to having unprotected sex with an unfamiliar partner. Out of these 95 respondents, only 23 (24.2%) have gotten an HIV test. There were only 3 IV drug users, only 1 of whom had an HIV test. Between different schools, students from the private school Andina were more likely to get HIV test than students from the public school UNSAAC ($p < 0.01$).

The most often cited sources of education regarding sex and HIV were subdivided between males and females. For both genders on both topics, school was the most often cited. The media and the parental unit of the same gender as the respondents were also cited in the top 4 for both genders on both topics. For both males and females they reported that friends were a common source of sex education while doctors were a more common source of HIV education. For males regarding sex education, the most commonly cited sources were school (46.18%), media (42.17%), friend (43.57%), and father (29.32%). For males regarding HIV education, the most commonly cited sources were school (63.05%), media (50.60%), doctor (32.13%), and father (30.52%). For females regarding sex education, the most cited sources were school (64.66%), media (53.41%), mother (41.77%), and friend (37.75%). For females regarding HIV education, the most cited sources were school (71.49%), media (58.23%), doctor (32.93%), and mother (32.13%). In Cusco, the only places to receive HIV testing are at the hospitals. Only 75 out of 235 respondents (31.9%) correctly identified hospital as a place that offered testing. Those who knew where HIV testing was offered were more likely to get tested ($p = 0.04$).

The average score on the HIV knowledge questionnaire (HIV-KQ) was 12.14 (out of 17), median score: 13. Demographic factors that correlated with statistically significant ($p < 0.05$) higher score on the HIV-KQ included: being from an urban area, being in a relationship, being sexually active, drug use current or former (87 respondents in total, all but 4 being marijuana only), and knowing where to get an HIV test. There was no difference in score between UNSAAC and Andina. However, students from either school scored higher than students from any of the other schools. The questions least answered correctly (% correct in parenthesis) were regarding: transmission through sneezing and coughing (63%), transmission through oral sex (55%), latency period before a test will show true positive (49%), and vertical transmission (41%).

Part 3: A total of 54 students participated in focus groups. Responses are recorded as the number of people who introduced an idea, or whom agreed with it once it was introduced. Students agreed that they received more hours of teaching while in high school, but that these courses were not sufficient or open enough. Many cited the one hour lecture they received during university orientation as useful but not sufficient. The generally consensus was the more open, liberal education was more informative and effective. Only one student mentioned having received abstinence only education at their Catholic high school. One student mentioned that “there was enough information about how [HIV] is contracted and prevention, but it could have been explained more.” Students said they were most often taught by their parents (6) or school psychologists (8).

The overarching consensus was that students felt there needed to be more education and it needed to be more in-depth. Students mentioned wanting to learn more about almost every topic- from anatomy, to prevention (especially contraception) to disease effects on the body. Students agreed they wanted someone with experience (6) or a medical professional (5) to be the educators. The majority agreed that teaching should start by ages 10-11 or 6th grade (9). Multiple students said it needed to go “little by little.”

While many agreed that the internet is easy to use, they know it is not a reliable source of information and therefore do not trust it (9). In contrast, 13 students expressed that RPP, the Peruvian public radio, had good, reliable programs for information. Students noted that only the international channels (including the Discovery Channel and BBC) on TV had information about HIV/AIDS, not the national ones.

Students feel that when condoms are not used it is either because they lack information (10), because it feels uncomfortable (10) or because of barriers to access (8). Students are able to identify reasons a person should have an HIV test (every 6-12 months when having sex, especially with multiple partners), but usually only one or two reasons were ever produced by a single group. The consensus is that people do not get HIV tests because they are afraid of the results (9). Only one mentioned not being sufficiently informed and one mentioned fear of discrimination. People agree that persons with HIV are discriminated against and they feel this is usually due to a lack of understanding HIV/AIDS. One student mentioned that “even health care professionals discriminate, they don’t want to take care of those patients.”

Conclusion: Overall score on the HIV knowledge questionnaire (HIV-KQ) was slightly lower in our group (median score 13/17) than another study that utilized the HIV-KQ-18 in a group of young IV drug user (median score 15/18)[5]. Being part of a higher risk group (being sexually active or actively using drugs) was actually associated with a higher score on the HIV-KQ. More intuitively, being from an urban setting, being in a relationship, and knowing where to get an HIV test were associated with a higher score on the HIV-KQ. Between different schools, students from the most prominent schools (UNSAAC and Andina) had higher scores on the HIV-KQ than students from other institutions. This suggests that one potential way to target future education initiatives is students attending technical schools, from rural areas, or younger students that have not yet entered into a sexual relationship.

Although school is the most often cited source of information regarding sex, a large proportion of respondents still did not cite it. It appears that sex education is happening in both high schools and universities, but unfortunately the better information from universities is limited to only a single, one-hour course. Many students identified high school as a time when sex and HIV/AIDS education could be improved. Media is another important source of information and ranks ahead of friends, family, and doctors. Many students suggest making it known which Internet sites are reputable as well as taking advantage of radio stations such as RPP.

Our data showed the proportion of youths in Cusco who are sexually active and at risk for HIV and other STIs is significant. The overall prevalence of sexually active youths (70%) is on the high end of reported statistics (up to 75%) [2]. Unfortunately, HIV testing is not very common (about 1 in 4). More disturbingly, only 31.9% of respondents reported the right location to get an HIV test. Respondents who answered correctly were more likely to get HIV testing. Interestingly, no student mentioned that not knowing where to get an HIV test as being a barrier. Although students could identify high-risk behaviors that would warrant testing, testing rates do not increase in high-risk

groups. Students from the private Universidad de Andina were more likely to get HIV testing. This would suggest that information about where and how to get tested, especially among lower-income or technical students, could help increase the rate of testing.

There are several weaknesses of this study. First, although the HIV-KQ-18 is a validated questionnaire is validated tool to measure overall HIV knowledge (reference), it was never validated for the population we worked with. We eliminated a question regarding use of natural skin vs. latex condoms because natural skin condoms are not available for sale in Cusco. We deemed this an irrelevant question and did not replace this with a different question, giving us a survey of 17 questions. When compared with the results of the KQ-18 survey, our study population did significantly worse (>5% difference in overall percentage of correct respondents) on 5 questions, all of which we deem to be fundamental knowledge regarding HIV. The 17 questions cannot address all areas of knowledge deficiency, but this was never our goal. Rather, we used the survey as a measure overall knowledge. Analysis of the data could also be improved by a multi-variable regression analysis to identify independent factors that affect HIV knowledge. However, from a practical standpoint, it matters little whether being part of the subgroup is an “independent” predictor of HIV knowledge. These subgroups represent potential targets for education initiatives. For example, students from rural areas have lower scores on the HIV questionnaire. It could be that the reason they know less about HIV is because they are less likely to be sexually active or that their parents have less education. Nevertheless, education initiatives could target youths in rural areas.

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Year-Out Research

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Perspectives of South American Hospitals Hosting Foreign Rotators in Emergency Medicine

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Study Objective: Emergency Medicine (EM) in the United States (U.S.) is increasingly becoming an international field. The number of fellowships in International EM is growing along with opportunities for EM residents to complete international electives. The impact on foreign host institutions, however, has not been adequately investigated. The objective of this study is to assess the experience of several South American hospitals that host foreign rotators in their Emergency Department (ED).

Methods: Anonymous, semi-structured one-on-one interviews were conducted with 24 physicians in the ED of four hospitals in Peru and Argentina. All participants had experience working with foreign rotators. Interviews were analyzed qualitatively and coded for common themes.

Results: Three department chairs, 6 residents, and 15 attending physicians were interviewed. Two broad theme categories emerged: Barriers and Benefits. *Knowledge Sharing about Emergency Medical Systems*, including differences in pre-hospital care, triage and implementation of clinical guidelines, was the most common perceived benefit, identified by 78% of respondents. 58% reported *Medical Knowledge Transfer* in the form of discussions, lectures, or skills demonstrations given by visiting physicians as a benefit. Hosts also enjoyed teaching rotators about common pathologies, procedures, and clinical practices utilized in the host hospital. 42% believed the formation of *Long-Term Relationships* that led to future rotators, collaborations, and research was another advantage. The most common barrier was *Language Proficiency*, cited by 70% of interviewees. Spanish proficiency related directly to how involved rotators became in patient care (i.e. taking a history, participating in rounds) but was not completely prohibitive, as a majority of physicians interviewed felt comfortable speaking in English. Another disadvantage, discussed by 58% of host physicians, was a *Lack of Reciprocity* due to the difficulty of completing a rotation in the U.S. as well as failed attempts at building long-lasting relationships with other institutions. Lastly, 25% preferred if a rotator stayed for at least a month and came in the last year of residency or while already in practice. This latter preference increased knowledge transfer from rotator to host.

Conclusions: This is the first study that we are aware of that investigates the perspectives of residents and physicians working in Emergency Departments in South America that host foreign rotators. It identifies clear benefits and barriers by the hosts themselves. Language proficiency improved a rotator's ability to participate in direct patient care and a rotation completed later in residency for at least a month was preferred. Hosts enjoyed knowledge sharing about EM systems and practice. They expressed a desire to form long-term, reciprocal institutional relationships. The difficulty of rotating in U.S. EM departments, however, was a major hindrance. In the future, EM residency programs and professional organizations may identify ways to facilitate foreign rotators coming to the U.S. An additional study that simultaneously measures experiences of both rotators and hosts in an established EM international elective might lead to further insights into how to improve EM international educational exchanges.