Findings: Comparison of the surveys demonstrated an increase in preparedness after the educational intervention. Knowledge test scores also increased in all four lectures. Further questioning extracted a desire for more video lectures and an inclination among the registrars to create their own.

Interpretation: Providing instructive videos easily accessible from a computer creates a flexible learning environment and increases the availability of educational material in a low-resource setting.

Funding: Stanford Department of Anesthesiology, Perioperative and Pain Medicine, Stanford Center for Innovation in Global Health.

Abstract #: *2.013_TEC*

The global burden of lipodystrophy, a rare disease

Cristina A. Meehan[1], Elaine Cochran[2], Phillip Gorden[1], Rebecca J. Brown[1]; [1]National Institutes of Health, [2]National Institute of Diabetes and Digestive Kidney Diseases, Bethesda, MD

Background: Lipodystrophy is a rare disease in which patients lack subcutaneous adipose tissue. These patients represent an extreme model of the metabolic syndrome (insulin resistance, dyslipidemia, fatty liver) seen in obesity. Management of lipodystrophy is challenging, and effective therapies such as recombinant human leptin (metreleptin) and concentrated U-500 insulin are not globally available. For over 40 years, the National Institutes of Health (NIH) in the US has studied patients with lipodystrophy from around the world. We herein describe the demographics of lipodystrophy patients seen at NIH to help understand the global burden of this disease, and discuss challenges in medical management worldwide.

Methods: We reviewed demographics of patients who participated in NIH studies between 1976 and 2015 and global availability of therapies.

Findings: Of 193 patients, 79% were female and 21% were male. Mean age was 34.6 ± 18.9 years. 28% had acquired lipodystrophy and 72% had genetic lipodystrophy. Ethnic distribution was 60% Caucasian, 13% Hispanic, 11% African-American, 5% Middle Eastern, 4% Southeast Asian, 2% each African, Caribbean, and Native American, and 1% other. 28 countries were represented. The geographic distribution of residence was 77% Americas , 14% Europe, 4% Asia, 3% Middle East, 2% Africa, , and 0% Oceania. Of the 150 patients from the Americas, 83% were from the US, 9% South America, 3% Central America, 3% Canada, and 1% Caribbean.

Interpretation: Access to metreleptin therapy depends on country-specific drug approval. Currently, metreleptin is approved only in the US for generalized lipodystrophy, and in Japan for all lipodystrophy types. It is available in other countries for compassionate use, including the UK, France, Spain, Germany, Italy, Serbia, and the Netherlands. Patients from other regions may travel to the US or elsewhere to obtain metreleptin via clinical trials. Many patients with lipodystrophy also require U-500 insulin for diabetes. U-500 may be obtained via Lilly country representatives in countries where it is not marketed.

The NIH dataset demonstrates the worldwide burden of lipodystrophy. NIH has been a leader in the treatment of lipodystrophy; however, resources available to treat patients at NIH are not always available in patients' home countries.

Funding: National Institutes of Health, National Institute of Diabetes and Digestive Kidney Diseases.

Abstract #: *2.014_TEC*

Outcomes of endemic Burkitt lymphoma patients treated using a patient-oriented approach

I. Mutyaba[1], S. McGoldrick[2], E. Krantz[3], M. Ulrickson[4], S. Gerdts[3], A. Omoding[1], F. Geriga[1], J.B. Kambugu[1], J. Orem[1], C. Casper[3]; [1]Uganda Cancer Institute, Uganda, [2]Seattle Children's Hospital, [3]Fred Hutchinson Cancer Research Center, United States, [4]Banner MD Anderson Cancer Center

Background: Endemic Burkitt lymphoma (BL) is the commonest childhood cancer in sub-Saharan Africa. BL tumors are fast growing but very responsive to treatment and potentially curable if treated early. However, survival is poor with approximately half alive at one year post diagnosis. Retrospective data on patient outcomes are limited by misclassification of diagnosis, poor access to cancer chemotherapy, and loss to follow-up.

Aim: Through the implementation of a comprehensive clinical care project we sought to improve access to care and survival for children with BL at the Uganda Cancer Institute (UCI).

Methods: The Burkitt Lymphoma Project aims to address: adherence support, nutritional support, treatment gaps, improved diagnostics and quality control through data collection. We used proportions to summarize key project outputs and Kaplan-Meier methodology to estimate 1-year survival.

Results: We followed 121 children with confirmed BL from July 2012-July2014. Baseline median age was 7 years (range 1-18); 61 % were male, and 52% had early stage disease. First-line chemotherapy {cyclophosphamide, vincristine, and methotrexate (COM)} was given to 86% (104/121) children; 12% died before initiating chemotherapy, and 2% refused treatment. All patients and their families received adherence support consisting of reminder calls and transport reimbursement for clinic visits. Of 657 chemotherapy doses dispensed, 28% were supplied during shortages. Of 104 patients initiating COM, 75% completed treatment (6 cycles of COM), 3% were switched to second line therapy before completing COM, 10% died during treatment, 8% were lost to follow-up and 4% refused further treatment. Of the 76 patients restaged after 6 cycles of COM: 76% had complete response (CR), 16% partial response, 8% had stable disease or progressive disease. BL relapsed before the 1-year anniversary post diagnosis in 21% of patients who had CR to COM. One-year overall survival was 51%, 95% CI (37%, 64%).

Interpretation: Addressing gaps in the existing treatment infrastructure for BL at UCI resulted in an improved level of adherence and decreased number of patients lost to follow-up. COM induces a sustained complete response in only 60% of BL patients completing treatment. Survival outcomes remained poor, likely due to inferior treatment regimens and late presentation.

Funding: Burkitt Lymphoma Fund for Africa and the Martin-Fabert Foundation.

Abstract #: *2.015_TEC*