Exploring Perceptions and Experiences with Research Ethics in Bolivia

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Health systems service learning in Shanghai—Lessons from an undergraduate experiential learning program in China

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Background: After Hurricane Katrina, 80% of New Orleans, including both of Tulane’s Uptown and Downtown campuses were under water. When classes resumed in January 2006, Tulane students, faculty, and staff returned to a city in ruins, but they returned to a university committed to rebuilding both the school and New Orleans.

A major focus of Tulane University’s rebuilding plan became the creation of a service-learning requirement for all undergraduate students, regardless of major. As New Orleans’ largest employer, Tulane University first directed students and their projects toward helping the areas and organizations within the city and the metro area. However, as the city of New Orleans emerged from the post-Katrina devastation, Tulane began to widen the reach of this program to other parts of the state, the nation, and eventually internationally.

Structure/Method/Design: In 2011, Tulane partnered with Fudan University in Shanghai and Shandong University in Jinan to create one of the first international service-learning opportunities to be made available to Tulane undergraduates. Now entering its fourth year, the program continues to expand its number of students, relationships with Shanghai health care institutions, and opportunities for young scholars to make a difference in local communities.

Results (Scientific Abstract)/Collaborative Partners (Programmatic Abstract): Among the 89 respondents, 53.9% were undergraduate, 46.1% were graduate students, 67.4% were female and the mean age was 22 years. Less than half (40.4%) of the respondents reported that LMIC partners or community representatives had been involved in defining the research objectives; 74.2% of respondents had received some form of research ethics training prior to their trip; and 59.0% submitted their research protocol to the local IRB when one existed (compared with 70.9% who submitted to the Yale IRB). While 67.4% of respondents stated that they planned to disseminate results to their host institution, community, or in a local publication, only 27.0% had done so. In bivariate analysis, students who sought LMIC partner involvement in the definition of research objectives reported feeling that their Yale advisor was not enthusiastic about their research (41.2% vs 11.5% among those that did not involve partners in defining objectives, P = 0.001), communicated less frequently with their Yale advisor before their research experiences (Mann-Whitney U test P = 0.001), and felt less prepared to deal with ethical dilemmas in the conduct of their research (Mann-Whitney U test P = 0.013). Those students who had disseminated results locally were more likely to have communicated with students who had previously visited the site (84.2% vs 55.6% of those who did not disseminate locally, P = 0.029) and to feel that they would have benefited significantly from a post-experience debriefing with experienced faculty or students (50.0% vs 23.0%, P = 0.012).

Summary/Conclusion: According to student reports from a sample of undergraduate and graduate students, guidelines for global health research are not being uniformly applied. Support and mentoring by faculty advisors and peers should be further explored to ensure best practices and are being applied and that students receive appropriate training and guidance prior to undertaking research projects in LMIC settings.

Exploring perceptions and experiences with research ethics in Bolivia

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Background: In Bolivia, there is increasing interest in the necessity of incorporating research ethics into study designs and procedures, but there is minimal data on the perceptions and experiences of Bolivian health science faculty, researchers, and national health administrators on research ethics. The Touro University California (TUC) Public Health Program is partnering with Bolivian universities to develop a comprehensive Research Education Ethics Program. In 2013, The Universidad Mayor de San Andre’s received a National Institute of Health/Fogarty International Center Planning Grant award to develop the program. The two central aims of this program needs assessment are to describe the perceptions of and experiences with research ethics among study participants and to assess the relationship between participants’ professional roles and their perceptions and knowledge of research ethics. Participants’ perceptions of the functions of Research Ethics Committees (protecting human subjects rights, ensuring the social and scientific value of research, etc) and study participants’ ideas for educational/learning needs were also described. The study has been implemented, data collection completed, and data analysis in process. Preliminary results show an immediate need and interest for research ethics capacity building and education in Bolivia.

Structure/Method/Design: This is a cross-sectional study using an online survey completed by approximately 200 Bolivian health science faculty, researchers, residents, and health administrators. Survey domains include demographics, perceptions and experiences related to research ethics and the function of research ethics committees, and knowledge of research ethics including course levels, content, and teaching methodologies. Descriptive statistics were used to describe
study participant characteristics and the key variables referred to above. Chi-square tests will be used to assess the relationships between participant characteristics and perception and knowledge indicators measured quantitatively using scales.

**Results (Scientific Abstract)/Collaborative Partners (Programmatic Abstract):** Universidad Mayor de San Andres

**Summary/Conclusion:** Challenges identified include insufficient knowledge, academic support, expertise, regulation, and funding. Study findings describe the current research ethics needs and practices in Bolivia and facilitate the development of a sustainable research ethics education program.

**CSIH MentorNet: Impact of an innovative national global health mentorship program on students and young professionals**

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**Background:** In 2011, the Canadian Society for International Health (CSIH) created MentorNet, a national global health mentorship program that connects students and young professionals (SYPs) with experts in fields relevant to global health. MentorNet recognizes that global health encompasses a diverse array of disciplines, and seeks to bring together mentors and SYPs from a wide range of health-related professions, including nursing, nutrition, epidemiology, and the social sciences. The program aims to expand SYPs' awareness of the global health field, increase SYPs' confidence in pursuing a global health career, encourage knowledge transfer between new and experienced professionals, and improve SYPs' understanding of global health issues.

**Structure/Method/Design:** MentorNet is run by a volunteer steering committee (SC) of young global health students and professionals living across Canada, many of whom have previously participated in the program. SC members are responsible for program coordination and the recruitment, selection, and matching of SYPs and mentors. SYP admission is competitive, and successful applicants are matched with mentors based on their interests and geographic location. Over a 9-month period, mentor-SYP pairs receive monthly global health modules from SC members, which prompt them to critically engage with global health issues, reflect on their career goals, and discuss challenges and opportunities in global health practice in Canada and internationally.

**Results (Scientific Abstract)/Collaborative Partners (Programmatic Abstract):** Not applicable

**Summary/Conclusion:** Following a successful pilot year (2011-12), during which MentorNet developed a module-based global health curriculum and matched 30 SYPs, a second cohort of 35 SYPs completed the program in 2012-13. Pre- and post-evaluation results from years 1 and 2 indicate that the program has consistently improved SYPs' awareness of opportunities in the global health field, enhanced their understanding of global health issues, increased their interest in pursuing a career in global health, and expanded their contacts and networks in global health. Ongoing challenges identified by participants include geographic/time differences and time constraints/competing commitments. The SC is addressing these challenges by factoring geographical location into the matching process, and working with pairs to tailor the scheduling of modules. After 2 years, MentorNet has proven to be a valuable initiative for supporting Canadians SYPs to become leaders in global health, and provides a low-cost, youth-led program model to build global health capacity.

**Health education for sickle cell disease: Strategies to support families and health care workers in Tanzania**

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**Background:** Sickle cell disease (SCD) is a major public health concern in Tanzania, with an estimated birth prevalence of 7/1000. There is limited awareness among health care workers and the community. This study aimed to identify the needs of children living with SCD and their families, health care workers, and teachers to better understand the importance of awareness, education, treatment access, and proactive lifestyle modifications.

**Structure/Method/Design:** Method: This community-based study included two areas in Tanzania: a rural community in the Coast region and a tertiary-level health facility in an urban setting in Dar es Salaam. We aimed to enroll 30 participants: 10 children (0-18 years) with SCD, 10 parents/caregivers of a child with SCD, and 10 health care providers and teachers overseeing individuals with SCD. Purposeful sampling was used to identify children with SCD and their families through local health services. Associated allied health care providers and teachers were identified using snowball sampling. Each participant was interviewed using one of four predefined questionnaires specific to their group. Open-ended questions beyond the structured interview were used to expand on key themes.

**Results (Scientific Abstract)/Collaborative Partners (Programmatic Abstract):** Muhimbili University of Health and Allied Sciences

**Summary/Conclusion:** Results: A target number of participants was not reached due to short time frame in the targeted communities and limited access to participants. Two children, one parent, and seven health care providers participated (n = 10). Children indicated they had limited knowledge about SCD, particularly when describing pain severity. Parents highlighted the deficit in support from the local health care facility. Participants identified a need for better SCD management protocols and nutritional education. Rural health care providers had limited knowledge of the importance of a high index of suspicion to improve diagnosis of SCD and on the severe complications of disease particularly infection, severe anemia, and malnutrition. Urban health care providers prioritized increasing understanding and efforts to develop awareness at the national level, particularly improving diagnostic facilities throughout the country, as well as encouraging patients’ adherence to clinics for follow-up and advice. They also identified multiple challenges in the management of SCD, including underdiagnosis of SCD, misdiagnosis as malaria, and significant lack of knowledge about SCD.

**Conclusion:** Gaps in knowledge about SCD were identified among patients, families, and health care providers in rural Tanzania. Knowledge of disease severity is low, which increases the risk for other