Exploring Perceptions and Experiences with Research Ethics in Bolivia

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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 Andrés 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
Universidad Mayor de San Francisco Xavier
Universidad Mayor de San Simón

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/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
University of Alberta
Students’ International Health Association
Community partners in villages who participated

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