



MOTHERING & ALBINISM

Newsletter Fall 2019

Welcome to the first of several newsletters on our [Mothering, Albinism, and Human Rights project](#). We are thankful for the passion, expertise, and time that you bring to this project and do not take any of that for granted! At the Canadian Conference on Global Health in Ottawa this month, one of the speakers reminded us of Margaret Mead's words: "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has." May this encourage and inspire each of us in our work – separately and collectively.

Announcements

Upcoming Fieldwork to Tanzania & South Africa

Thanks to our Tanzanian and South African partners, we were able to arrange for further fieldwork in Tanzania, as well as an initial visit to South Africa from Oct 27 to Nov 21! Emma leaves for Dar es Salaam on October 26 and will collect more data (e.g., interviews with several more faith leaders) prior to our research and ethics clearance expiring. Barb and Sheryl will join her for 10 days in Tanzania from Nov 8 to 16, focusing on consultation, data analysis, and knowledge mobilization.

From Tanzania, Emma will travel to South Africa to meet with Innocentia in Pretoria and Dr. Kromberg's colleagues and Nomasonto in Johannesburg.

We have received REB approval from Trinity Western University. REB review at the University of Toronto for Dr. Tettey is in process. In Tanzania, we have research clearance (which includes REB) effective to November 15, 2019. Emma will work with Innocentia at the University of Pretoria to obtain REB and will discuss this process with our colleagues at the University of Witwatersrand as well. Likewise, we will work with partners in Ghana, as that phase of the project nears.

We will have a fresh fieldwork update for the team when we meet online at the end of November!

Consultation Meeting with NGO Partner

Sheryl, Barb, and Emma discussed preliminary findings and analyses with IK Ero and Don Sawatzky (Director of Operations, UTSS) in early October. The purpose of this meeting was to assess whether we are on the right track as we continue in the analysis of our collected data — recognizing that feedback and input at this stage and ongoing is critical. We framed the consultation around this question: What are we missing by reading data from our Northern position? Don and IK were generous with their time, knowledge, and feedback. We will continue these consultation meetings with our research partners as the project progresses.

Presentation at 25th Canadian Conference on Global Health, Ottawa

Emma, Sheryl, and Barb prepared a presentation for the 25th Canadian Conference on Global Health in Ottawa, Ontario entitled: Engaging the experiences of mothers impacted by albinism in Tanzania: An ethnographic study towards health equity. This conference was an excellent forum to present the voices of mothers who shared their experiences with Emma and Jane earlier this year. The project was well received and questions pertained to reflexivity, partnering organizations, the role of poverty, and differences between urban and rural experiences.



Africana Womanism

A few of you expressed curiosity in reading more on Africana Womanism (Hudson-Weems, 1992). Africana Womanism captures well the feminist lens in a Tanzanian context versus many Western feminist frameworks as it considers values placed on family, community, and mothering.

Knowledge Mobilization via Social Media

We have hired a communications student, Justin Chase, to assist us with branding the project and developing a project blog. Justin designed the logo you see on this newsletter, and also designed the newsletter. Thank-you!

We plan to have the blog operational by mid-November with initial posts completed while we are in Tanzania and South Africa. We are using the following hashtags for our work: #stillstandingstrong #actiononalbinism #motheringandalbinism

Update on IK's UN Mandate

Ikponwosa (IK) Ero is a project co-lead and the UN Independent Expert on the enjoyment of human rights by persons with albinism.

The [African Union](#) officially adopted the Regional Actin Plan on Albinism! This is a milestone.

Albinism Worldwide questionnaire was completed by 90 civil society groups. IK and her team filed a [UN report](#) based on the findings.

IK has also submitted a [report on the socio-economic](#) situation of persons with albinism.

We continue to be in awe of IK's ability to strategize, collaborate, and champion the rights of persons with albinism.

Introducing our Undergraduate Research Assistant: Meghann Buyco

We would like to introduce Meghann to you. She is in her 4th year at our School of Nursing here at TWU. While taking a course with Sheryl this last May, she learnt about this project and voiced interest as a woman with albinism herself. Originally, from the Philippines, she moved to Canada with her family as a teenager. She is summarizing the coded data from our meta-narrative literature synthesis – a massive and crucial job that is helping us as we write up the results. Her perspective as a woman with albinism is invaluable to this project. We are very thankful to have her onboard.



Final Words

As a collaborative, intersectoral team we value critique, questions, and feedback as we proceed on this important work collectively. We will continue to engage with you on our processes, as we complete fieldwork in Tanzania and then set up for fieldwork in South Africa.

Peace to you and yours.

- Sheryl, Barb & Emma

Project Team

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