Consortium on Law and Values in Health, Environment & the Life Sciences
2011-12 Student Proposal Cover Page

Applicant Information

Applicant Name: Emily Sandberg
Email: sandb135@umn.edu

Project Title: Genetic Counseling in South Africa: Comparison and Analysis of Session Goals between Patients and Genetic Counselors: A Two Part Investigation

Department: Genetic Counseling
College: MCDB&G; University of Minnesota, Twin Cities

Home address:
5241 Lincoln Dr, Apt 107
Edina, MN 55436

Faculty advisor name: Bonnie Leroy
Email: leroy001@umn.edu

Dept. Head's name: Michael O'Connor
Dept. Head's email: moconnor@umn.edu

Dean's name: Dean's email:

How did you hear about this funding opportunity?
From Advisor, Bonnie Leroy

Funding

Total amount of funding requested: $9,961.58

Executive summary (maximum 200 words)

The purpose of this research is to determine the importance of REM goals and the extent to which they are accomplished in genetic counseling practice in South Africa. It is with cultural competence and sensitivity that genetic counselors will be able to establish relationships with patients that foster mutual trust, respect and understanding that are necessary for successful genetic counseling interactions. This two-part study will explore perspectives of individuals from two populations – genetic counselors, and genetic counseling patients. In Part 1 I will administer an anonymous online survey to South African genetic counselors to investigate four major research questions. My colleague, Stephanie Goettl, will address part 2 of the study where South African adult patients who have received genetic counseling will be recruited through genetic counselors. They will be invited to participate in a semi-structured face-to-face interview exploring their genetic counseling experience. This research aims to contribute to the body of work that identifies the goals and objectives of genetic counselors across the world, while continuing to build upon global connections and resources for the greater genetic counseling community.

Approvals

Check all appropriate approvals required for your proposal. Approvals must be obtained prior to receipt of funding. If you have applied for approval but have not yet received it, indicate that below.

IRB
Yes ☐ No ☑ Application pending

IACUC
Yes ☐ No ☑ Application pending

Other
Yes ☐ No ☑ Application pending

Checklist

☒ The proposal is 1000 words or less excluding budget, biographies, references and citations.
☒ The proposal includes a work plan with a specific timeline using months or quarters to identify work to be done and completion dates.

☒ The proposal includes a 1-2 paragraph biography of the applicant and all co-investigators.

☒ The budget form is complete including the funds sought for this project, other pending applications for this project, and the amount/source of matching or other funds.

☒ The applicant's faculty advisor is copied on the application email. Professional students w/o advisors check NA.

☒ All necessary approvals are pending or received.
Project Proposal

Title: Genetic Counseling in South Africa: Comparison and Analysis of Session Goals between Patients and Genetic Counselors: A Two Part Investigation

By: Stephanie Goettl and Emily Sandberg

Faculty Advisor: Bonnie S. LeRoy M.S., and Patricia McCarthy Veach, Ph.D.

Background and Research Question:

Genetic counseling has been a formally recognized profession for approximately four decades. In this constantly evolving profession, genetic counselors strive to remain current with scientific information and understanding the complexities of human nature. Genetic counselors are often the health care professionals who begin discussions of the underlying genetic basis of conditions and discuss implications for individuals and family members. This field is growing globally, as increases in availability of genetic tests and services raise patient demand for support and interpretation. Genetic counseling strives to integrate the following: interpretation of family and medical histories to assess the chance of disease occurrence or recurrence; education about inheritance, testing, management, prevention, resources and research; and counseling to promote informed choices and adaptation to the risk or condition. Although genetic counseling has a definition that characterizes its services, there is also a need for a deeper understanding of the model of practice, including but not limited to, describing why and how the services are delivered to patients.

A recently proposed Reciprocal Engagement Model (REM) identifies 17 goals that have been recognized to guide genetic counseling practice (McCarthy Veach et al., 2007). This model was informed by a consensus group of program directors from 20 accredited genetic counseling programs across North America and was originally funded by this Consortium. The model was validated among North American genetic counselors who completed a survey investigating the extent to which REM goals reflect their clinical practice (Geiser et al., in preparation). The importance of REM goals for genetics professionals in the Middle East was also investigated recently (Hajj et al., in preparation). Such studies provide a starting point for learning about genetic counseling at a transnational level.

Our proposed qualitative research extends the work of Geiser et al. (in preparation). This will be the first investigation of the relevance of REM goals in the emerging South African genetic counseling practice. The profession in South Africa is relatively young, with an estimated 20 practicing counselors. The goal of our research is to support work in legal, ethical, social, and policy implications of genetic counseling within South Africa. We expect the findings will contribute to advances in knowledge, public understanding, and sound policy as the profession evolves in South Africa.

Methods:

This two-part study will explore perspectives of individuals from two populations – genetic counselors, and genetic counseling patients. In Part 1 we will administer an anonymous online survey to South African genetic counselors (~N=20) to investigate four major research questions: (1) How important is
each REM goal to their practice? (4-point scale) (2) How often do they achieve each goal in their practice? (4-point scale) (3) What do they regard as a successful genetic counseling session? (open-ended) and (4) What do they regard as an unsuccessful genetic counseling session? (open-ended).

Survey respondents will be invited to participate in a follow-up 20 minute phone interview to expand on these goals in light of their cultural implications. In Part 2 of the study South African adult patients who have received genetic counseling will be recruited through genetic counselors (~N=20). They will be invited to participate in a semi-structured face-to-face interview exploring their genetic counseling experience. The main research questions are: (1) What were the patients’ objectives coming into the session? (2) Did the patients feel the REM goals were accomplished during the session? (3) How did the genetic counselor accomplish these goals? (4) What was most and least helpful about the session?

Descriptive statistics will be calculated for survey data and inductive analysis methods will be used for interview data.

Importance and relevance of the project:

The purpose of this research is to determine the importance of REM goals and the extent to which they are accomplished in genetic counseling practice in South Africa. Additionally, we will compare genetic counselors’ goals to the objectives of South African patients. Culture can strongly influence what a person perceives as “right” and “wrong” and therefore such perceptions may vary across cultures. Such differences come into play when people from diverse cultural backgrounds interact. A culturally competent approach and unified goals among practicing genetic counselors are essential to avoid ethical conflicts posed by competing values. The findings will be compared to studies of the REM in North America and the Middle East to obtain insight regarding practice similarities and differences on a global scale.

Regarding Part 2 of the study, identifying the goals of South African patients receiving genetic counseling is important for aligning professional and patient objectives for genetic counseling sessions. For individuals affected by or at risk for a genetic condition, having adequate knowledge or access to knowledge about a specific diagnosis, including its etiology and management implications, gives them power to respond to their life situation. What is said and how information is presented during genetic counseling sessions can have a significant impact on a person’s or a family’s ability to process, understand, and integrate information into their own personal life circumstances. Several authors have demonstrated the importance of unifying professional and patient objectives (e.g., Biesecker, 2001; Bernhardt, 2000; Peters, 2011; Resta, 2006; Wang, 2004). Understanding the goals of genetic counseling professionals and their patients can enhance the effectiveness of genetic counseling sessions.

It is important that genetic counselors be aware of cultural differences and how genetic counseling sessions are similar or different in other countries. It is only with cultural competence and sensitivity that counselors will be able to establish relationships with patients that foster mutual trust, respect and understanding that are necessary for successful genetic counseling interactions. This research aims to contribute to the body of work that identifies the goals and objectives of genetic counselors across the world, while continuing to build upon global connections and resources for the greater genetic counseling community.
Timeline for the Use of the Award:

February, 2012: Begin IRB process in South Africa

May, 2012: Send out survey to genetic counselors through public listserv

July, 2012: Travel to South Africa and complete patient and genetic counselor interviews. Begin transcribing interviews

August, 2012-May 2013: Complete transcription of interviews and begin analysis of results

January-May, 2013: Submit study for publication and present at National Genetic Counseling conferences

Applicants' Biography:

Emily Sandberg is a graduate student in the Master’s in Genetic Counseling program at the University of Minnesota. She holds a B.A in Comparative Religions from College of Saint Benedict, and studied abroad in South Africa during her undergraduate studies. Her research interests are deeply embedded in the integration of cultural sensitivity and healthcare. In returning to South Africa, her goal is to broaden the understanding of what constitutes an effective counseling session and the unique objectives of international genetic counselors. After the trip, she will submit the study for publication and present at National Genetic Counseling conferences. Emily is sincerely passionate about collaborating with international genetics professionals to better address the needs of our patients.

Co-researcher, Stephanie Goettl, received a B.S. in Molecular Biosciences and Biotechnology from Arizona State University. After graduating, she served in the Peace Corps in Mozambique for two years. While her primary project was teaching chemistry to high school students, she was also the National Financial Coordinator for science fairs, helping to organize many regional fairs throughout the country. Stephanie is currently a first year graduate student in the Master’s in Genetic Counseling program at the University of Minnesota. She is excited to return to Africa to use her new knowledge and skills to help provide South Africa with useful research and data to help guide the emerging field of genetic counseling, while learning firsthand about the diverse culture of this country.

References:


Peters, K F. (2011). A comparison of the background, needs, and expectations of patients seeking


### Project Title: Genetic Counseling in South Africa: Comparison and Analysis of Session Goals between Patients and Genetic Counselors: A Two Part Investigation

<table>
<thead>
<tr>
<th>Personnel costs</th>
<th>Description &amp; justification</th>
<th>Requested funding</th>
<th>Matching/other funding</th>
</tr>
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<tbody>
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<td>Salary = ___hrs x ____ hrly wage (current graduate student salary)</td>
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<td>2 co-investigator salary</td>
<td>75 hrs X $17 hrly wage (current graduate student salary)</td>
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<td>3 transcriber salary</td>
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<td>7 Supplies &amp; Services</td>
<td>phone and internet fees for conducting interviews; administrative fee for 2 at UCT</td>
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<td>8 Equipment</td>
<td>2 digital phone recorders (currently listed at $60.79 2/9/12 each on Amazon) and office supplies ($40). Equipment will be brought back to UMN for future research use.</td>
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<td>9 Travel</td>
<td>flight tickets for researcher and co-investigator to Cape Town July-August</td>
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<td><strong>Subtotal research supplies, equipment, travel, other</strong></td>
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<td><strong>11 TOTAL BUDGET</strong></td>
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1. Stipend justification. You must justify the amount of stipend you are requesting by identifying the number of hours you plan to work on the project and the hourly wage used for research assistants in your department. Include fringe benefits.

2-4. Identify all other personnel to be paid from this grant including interpreters, travel guides, etc. and justify their salary by identifying the number of hours they will work and the hourly wage. What is the hourly wage based on?

6. For colloquia, identify the number of speakers and the amount of honoraria you will provide.

7. Supplies and services. List out all supplies and their estimated costs. Explain in line 7 or in the body of your proposal what the supplies will be used for.

8. Equipment costs are allowable only if the justification clearly shows that the equipment is necessary for the project. Include explanation of what will happen to equipment at completion of project.